

Alberta Darling
Wisconsin State Senator
Co-Chair, Joint Committee on Finance

Senate Committee on Health and Human Services

Senate Bill 620

Wednesday, January 29, 2020

Thank you Chair Testin and committee members for taking the time to hear Senate Bill 620. The bill before the committee today creates licensure requirements for those practicing genetic counseling in Wisconsin.

Genetic counseling is a growing field in the United States. Nearly 5,000 genetic counselors are employed nationwide. Genetic counselors are trained to interpret genetic tests and provide guidance and support to patients. Genetic counselors are employed at university medical centers, hospitals, diagnostic laboratories, and physicians' offices, where they are a crucial part a patient's care team.

Under current law, there is no licensure requirement in order to practice genetic counseling. 23 other states, and counting, require licensure. Senate Bill 620 creates state licensure for genetic counselors in Wisconsin. The bill creates a seven member Genetic Counselors Affiliated Credentialing Board who would grant the license.

Medical professionals are licensed in order to protect patients and ensure access to qualified medical care. Genetic counselors provide crucial information and diagnoses to patients suffering from genetic conditions. In order to protect patients and ensure they are receiving accurate medical counsel, genetic counselors need to be licensed.

I'd like to thank Representative Steffen for his leadership on this issue. I would also like to thank the many genetic counselors who brought this issue to our attention and have shared their expertise and support for this legislation.



DAVID STEFFEN

STATE REPRESENTATIVE • 4TH ASSEMBLY DISTRICT

January 29, 2020

Chairman Testin and Health and Human Services Committee Members,

Thank you for holding a public hearing on SB 620 relating to the regulation and licensure of genetic counselors, creating a genetic counselors affiliated credentialing board, providing an exemption from emergency rule procedures, granting rule-making authority, and providing a penalty.

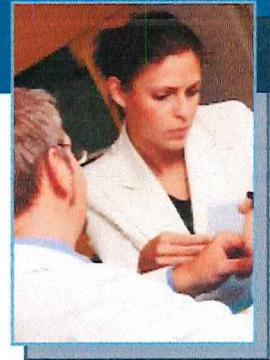
The United States is the world leader in providing genetic counseling services to individuals and families who are at risk of or suffering from genetic disorders or genetic-related birth defects. These advisory services are critical in the medical field, and are performed by highly-skilled, post-graduate scientists with a degree in Genetic Counseling. This growing group of medical professionals are employed throughout university medical centers, private and public hospitals, diagnostic laboratories, and physicians' offices.

Currently in Wisconsin, there is no licensure requirement for those practicing genetic counseling. As it is a growing practice, we believe Wisconsin should join the other 23 states that have implemented genetic counseling licensure.

SB 620 will add genetic counselors in the definition of "health care provider" and a person who practices genetic counseling is required to be licensed by a seven-member genetic counselors affiliated credentialing board, created by the bill. In addition, this bill requires the board to promulgate rules that define the standards of practice of genetic counseling and permits the board to define the scope of practice of genetic counseling.

I appreciate your consideration of this bill and I would be happy to answer any questions you may have.

Genetic Counselor Licensure



WHO ARE GENETIC COUNSELORS?

Healthcare professionals with a specialization in medical genetics and counseling

WHAT DO GENETIC COUNSELORS DO?

Discuss medical history and family history with individuals

Analyze family and medical history to determine risk for genetic conditions

Explain genetics, inheritance, and specific genetic conditions

Help patients determine their chance of a genetic condition or risk for a recurrence of that condition

Review available testing options, and facilitate genetic testing

Help patients with decision-making regarding management, prevention, and research opportunities

Provide psychosocial and supportive counseling

WHERE DO GENETIC COUNSELORS WORK?

Medical Clinics — hospitals, universities, private practices

Corporations — pharmaceutical firms, genetic testing companies

Non-traditional roles — public health departments, insurance companies, and healthcare companies.

The primary focus areas for genetic counselors are Obstetrics, Oncology, Pediatrics, Neurogenetics, and Cardiology

WHAT MAKES GENETIC COUNSELORS UNIQUE?

Holding a Master's degree in Genetics or Genetic Counseling

Having clinical experience in the areas of medical genetics and psychosocial counseling through their extensive training

Certification by the American Board of Genetic Counseling.

~100 genetic counselors with this advanced training and expertise are currently practicing in Wisconsin

WHY SHOULD GENETIC COUNSELORS BE LICENSED IN WISCONSIN?

To protect the public — there is no legal standard for who can represent themselves as genetic counselors

To ensure that individuals and families receive quality genetic counseling services

To provide the public with a means to identify qualified genetic counselors

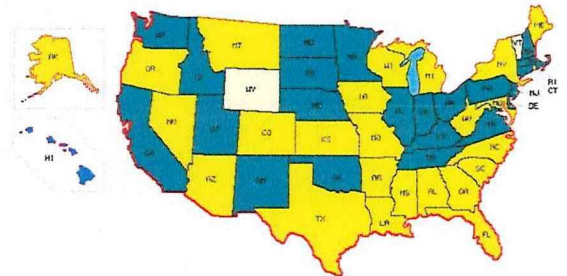
To ensure broad public access to genetic counseling services including rural Wisconsin

ARE GENETIC COUNSELORS LICENSED IN OTHER STATES?

22 States are currently issuing licenses

1 States have bills passed and are currently in rulemaking

- States w/ Licenses
- States in Progress
- States in Rulemaking



WHAT WILL IT COST THE STATE ?

Our bill is **BUDGET NEUTRAL** for state of Wisconsin

Cost analysis data shows genetic counseling by qualified professionals reduces national health care costs by over \$4 billion over 10 years.

January 29, 2020

**Testimony to the Senate Committee on Health and Human Services
Support for Senate Bill 620
Deborah Wham, MS, CGC, Manager, Aurora Genomic Medicine**

Good morning Chair Testin and members of the committee – thank you for the opportunity to testify today. Thank you also to the bill authors, Senator Darling and Representative Steffen, for authoring this much-needed legislation. My name is Deborah Wham, I am a Certified Genetic Counselor and the Manager of the Genomic Medicine Program for Aurora Health Care. I am here today on behalf of Aurora to voice our support for SB 620 – an important bill that will ensure that genetic counselors are appropriately regulated as the health care providers that we are.

For background, Advocate Aurora is among the largest not-for-profit health systems in the United States and the leading employer in the Midwest. We employ more than 70,000 people throughout Wisconsin and northern Illinois, and we see nearly 3 million unique patients per year. Our genetic counseling team consists of 11 genetic counselors here in Wisconsin.

Genetic counselors are healthcare providers with significant training and expertise in molecular biology, medical genetics and psychosocial counseling obtained through a 2-year Master's level program. Most students enter the field from a variety of undergraduate disciplines including biology, genetics, psychology, or public health. There are currently 40 accredited training programs in the United States and this number is growing as more academic centers of excellence institute a focus on precision medicine. The genetic counselor profession is one of the fastest growing in the United States. Since 2006 there has been 88% growth and it continues at a rate of about 7% annually. Currently, there are more than 4,000 genetic counselors in the United States. Locally, the University of Wisconsin has an accredited training program for genetic counselors.

Genetic counselors are part of a health care team providing information and support to individuals and families concerned about risk of genetic disorders. Genetic counselors:

- Collect and interpret family and medical histories,
- Identify individuals and families at risk of genetic conditions
- Explain inheritance and natural history
- Quantify chance of occurrence and recurrence
- Review available testing options
- Discuss management, prevention, and research opportunities
- Serve as patient advocates and refer individuals and families to community or state support services as appropriate

Genetic counselors are employed in a wide range of clinical care, academic, laboratory, research, and biotechnology settings. Within Wisconsin there are 114 genetic counselors, most of whom provide direct patient care in a variety of specialties including but not limited to Oncology, Obstetrics, Pediatrics, Neurology, and Cardiology.

The availability of genetic and genomic testing services is growing rapidly. Approximately 10 new genetic tests come to market each day with varying degrees of validity. Not only are there more tests, the complexity of testing is increasing.

The proposed licensure of genetic counselors in Wisconsin is consistent with the other 29 states that have enacted such laws, including all states bordering Wisconsin. In order to ensure the public is protected and that genetic counselors are able to practice to the full extent of their training in Wisconsin, we are hopeful you will enact SB 620.

Protect the Public

As the practice of genetic counseling grows in prevalence and complexity, minimum standards are needed to protect the public from potential harms that may result from untrained individuals attempting to provide this care. Some examples are:

- Misinformation regarding genetic risk or lack of risk;
- Failing to use CLIA certified laboratories or medical grade genetic tests leading to unnecessary interventions
- Misunderstanding of the implications of genetic information which can lead to:
 - unnecessary medical treatment and/or surgery
 - lack of prevention or disease monitoring strategies
 - irreversible management decisions
 - Avoidable fear, anxiety and guilt
 - Misunderstanding of risk for family members
- Inappropriately undertaking costly unnecessary genetic testing

Genetic counselors, with their specialized training, are ideally suited to work hand-in-hand with physicians and health care providers to ensure the delivery of high quality, up-to-date genomics services and to make sure that the patients utilizing these services are adequately informed. As such, they are key players in appropriately integrating genomics into health care and in avoiding the significant harm that can occur when genetic risk is not identified or when a patient is not properly counseled before genetic testing is done.

In addition, genetic counselors provide services that are cost-effective. They assure tests are utilized appropriately. Many health care providers request unnecessary testing or incorrect tests, which increases the cost of health care. Non-genetics health care professionals have also been demonstrated to underestimate patients' genetic risks because of ineffective family history evaluation. For many genetic conditions, 50% of first degree relatives (siblings, parents, children) of a person with a genetic mutation will also carry a mutation and are at risk to manifest the disease or transmit the mutation. Identifying those who carry a mutation offers the opportunity for preventive screening and treatment, thus lowering the chance of disease manifestations. Moreover, identifying those family members who do not carry a mutation eliminates the need for expensive clinical follow-up.

Improve Access to Genetic Counselors

Many health plans and hospitals require licensure to credential a healthcare practitioner. The absence of licensure impedes the delivery of genetic counseling services in these cases as genetic counselors are not permitted to practice to the full extent of their training. Many states see an increased demand for genetic counselors after licensure has been implemented.

For example, at Ohio State University, licensure allowed credentialing to occur and the oncology department was able to create several genetic counselor clinics that increased the number of patients seen in one clinic from 6 patient slots per week to 16 per week. They hired additional genetic counselors to ensure access was maintained.

Conversely, states without licensure may have a hard time attracting new graduates to the state. These circumstances could place Wisconsin at a disadvantage compared to other states and decrease patient access to the specialized health care services that genetic counselors provide.

In summary, genomics is changing rapidly and genetic counselors are key players in appropriately and effectively integrating genomic applications into health care. Clinicians and patients need to know that the genetic counselors they work with/see are adequately trained and up-to-date on genomic information. Therefore, Aurora Health Care, the Wisconsin Genetic Counselors' Association, and the National Society of Genetic Counselors respectfully request that you support this important legislation. Thank you again, for the opportunity to speak before you today. With that, I'd be happy to answer any questions.

January 29, 2020

**Testimony to the Senate Committee on Health and Human Services
Support for Senate Bill 620**

Christina Zaleski, MS, CGC, Director of Genetic Counseling & Client Services, PreventionGenetics

Chairman Testin and distinguished members; I am Christina Zaleski. I'm a certified genetic counselor from Marshfield, WI. I've been a WI resident nearly all of my life. I am currently the Director of Genetic Counseling & Client Services at PreventionGenetics. PreventionGenetics is in support of this bill. I also previously worked in both research and clinical settings as a certified genetic counselor. I am currently president of the WI Genetic Counseling Association. I appreciate the opportunity to testify in favor of Senate Bill 620 as this is important legislation that would provide licensure for Certified Genetic Counselors in Wisconsin. I am actually here today to represent our profession from my family's perspective to share a story of how this bill can help patients.

My grandma developed an enlarged, ballooned heart, referred to in the medical world as cardiomyopathy, when she was 39. At age 56, she was the oldest heart transplant recipient in WI. I was 13 at the time. Little did I know that her cardiologist at the time who let me spend time shadowing him in clinic showing me the tools he used to biopsy my grandma's new heart to check to make sure she wasn't rejecting it, would eventually be the same cardiologist that would trust me as a Certified Genetic Counselor to use the power of genetic medicine to save my dad's life.

At the time of grandma's transplant, she was told that a new heart may give her 5 bonus years to live. 26 years later she died of "old age". In college and graduate school studying genetics I learned that my grandma's heart problem might be inherited. Early in my career as a genetic counselor I worked hard to learn and document our full family history- to better understand if my family history would impact the chance of others having related heart issues. In talking with family and pulling together our family history I uncovered that my grandma's brother died in his sleep in his mid-60s and his autopsy showed a ballooned heart like my grandma's. Grandma assured me their hearts were caused by a childhood infection- scarlet fever I think is what she said, but as a genetic counselor having had specific training during graduate school, I was suspicious that there could be more to the story.

Two siblings with a relatively uncommon heart condition was enough for me to work with grandma's cardiologist to order genetic testing. While grandma was in good shape because she was doing well post transplant, I was concerned about my dad & his 5 siblings, not to mention 16 grandchildren and 21 great grandchildren that could be at risk for either an enlarged heart or life threatening related heart rhythm problems. Genetic testing performed over 15 years ago was negative. No genetic cause was identified. If this was most people and their encounter with genetic testing, this may have been the end of the story.

As a patient, I was relieved, but as a genetic counselor I understood the limitations of technology and the importance of staying up to date related to advances in genetics that could help my family. I banked grandma's DNA as a Christmas gift one year & grandma listed me as the representative who could have access to it if we ever needed to go back to it after her death. I know from my day to day work that most people are unaware of the value of DNA banking, but luckily I knew this was an option because of my training.

Fast forward our story several years. A few months after grandma's death about 5 years ago, my dad had a cardiac situation. There were concerns that he might be having a heart attack, so as you can imagine, this earned him a big cardiac workup. There were also concerns on whether he might have a heart rhythm issue that caused the problem. Our cardiologist was not convinced it was related to Grandma's condition, but there were some very subtle heart rhythm concerns including strings of irregular heartbeats. As a GC, I explained to my

dad and his care team that advances in technology have discovered new genes associated with cardiomyopathy. From my training and continued education in genetics I knew that these genes can cause a ballooned heart, but they can also cause serious, life threatening rhythm problems if left untreated. As many as 1 in 500 adults may have this condition, so knowing our family history and working alongside the cardiologist was critical.

Ultimately dad's cardiologist (who, as a colleague often leaned on me to help obtain family histories for his other patients, and the same cardiologist that I shadowed as a 13 year old when he took care of my grandma) consulted with a medical geneticist and my dad underwent genetic testing. We captured some of the newer genes that had been discovered after my grandma's testing. Together we made a good team to make sure my dad was getting the best care.

A complicated genetic change was found in a gene called TTN. The results were uncertain, but fortunately I had specialized knowledge of diagnostic genetic testing and knew some things we could do to help clarify it.

I suggested to my dad's care team that we go back and pull the banked DNA from my deceased grandma to compare her TTN gene to my dad's. They were thrilled that we had preserved that sample to test. Grandma carried the same genetic finding. Dad's cardiologist hesitated to act on this because of risks of doing more procedures, but together we decided that genetic testing results suggested that he may benefit from doing a more invasive test on his heart. My dad underwent a procedure where he was unconscious but his heart was stressed to see if a life threatening arrhythmia could be induced. It was a controlled environment that would tell us if he might benefit from having a pacemaker and an implantable defibrillator in his chest which would restart his heart if needed. The procedure showed that his heart was inducible, and he did earn himself a pacemaker & defibrillator that day. I can still remember the look on the cardiologist's face when he came out of the procedure to tell us the news- he said he was shocked. He also told me that he never would have guessed this outcome and had it not been for his genetic test results he never would have considered performing this procedure.

Our cardiologist told me he gave my dad an insurance policy in his chest that hopefully he would never need. Two years later that ICD saved my dad's life as it kicked in during his sleep and shocked him into a normal rhythm. He actually never even woke up when it went off. Mom remembered a big jolt in their bed, and when his recording was turned into the clinic for routine checking, it showed that the device did kick in and the "big jolt" my mom remembered then made a lot of sense. My dad would have died in his sleep that night had he not had that "insurance policy" inserted in his chest thanks to his genetic test results and the collaboration of his cardiologist with a genetic counselor.

Genetic counselors have advanced training in medical genetics and counseling to interpret genetic test results and to guide and support patients and healthcare providers seeking more information. Genetic counselors help patients make informed decisions with healthcare. From gathering our family history, to understanding the role for genetic testing, to understanding limitations of technology and then going back to readdress this with advancements, to later on helping the rest of a family understand the implications that all of this could have on their own health. This is the value that a genetic counselor brings to the healthcare team.

My personal story is an example of how GCs can collaborate (without infringing) on other subspecialties. I am grateful for the support from our cardiologist who was open to the power of genetic medicine and what I could contribute as a CGC. As a profession genetic counselors work closely with many specialties, many of which have also signed on in support of this bill. Our family cardiologist has also summited a letter of support for this bill.

I went into genetics to make a difference for patients. I am also grateful that my own genetic training as a GC may have actually saved my dad's life.

Thanks for your time today. I hope that you will work together to enact genetic counseling licensure to ensure that the citizens of WI receive quality genetic counseling services and help patients. We need licensure to increase access to these services for all of the citizens of Wisconsin. I hate to think of what my dad's outcome would have been had he not had access to a certified genetic counselor.

We thank the Chairman and this committee for your attention to this important issue, and we offer ourselves as a resource as you move forward.

GUNDERSEN HEALTH SYSTEM

January 29, 2020

Senator Patrick Testin, Chair
Room 131 South
State Capitol
PO Box 7882
Madison, WI 53707

Senator Dale Kooyenga, Vice-Chair
Room 310 South
State Capitol
PO Box 7882
Madison, WI 53707

Re: Support for Senate Bill 620

Chairman Testin, Vice-Chair Kooyenga, and members of the Senate Committee on Health and Human Services:

My name is Becky Pabst and I am the Lead Genetic Counselor at Gundersen Health System and a representative on the Wisconsin Cancer Council. I am here today representing both Gundersen Health System and the Wisconsin Genetic Counselors Association. I appreciate the opportunity to provide testimony on Senate Bill 620 in support of licensure of genetic counselors in Wisconsin.

Genetic Counseling licensure will protect the public. Licensure will ensure individuals and families can identify qualified genetic counselors in the State of Wisconsin and ensure our neighbors receive quality genetic counseling services.

For instance, last year a holistic wellness practitioner in Wisconsin advertised themselves as a genetic testing advisor, able to provide genetic cancer risk assessment and genetic testing with follow-up genetic counseling. This person joined the Wisconsin Cancer Council, portraying themselves as a genetic counselor and solicited business. Unfortunately, there are other individuals among wellness groups promoting genetic testing and interpreting results. One group specifically takes raw data from a non CLIA approved lab known as 23&me and re-interprets the data to advise people on their nutrition to impact medical management decisions. Even though some people may find value in this advice and are willing to pay to obtain this information it may harm patients and family members if the genetic testing data is misinterpreted or a patient's risk is over or underestimated. Genetic counselors have in-depth education,

training, and knowledge associated with a Masters degree in Medical Genetics and Genetic Counseling. These are direct examples of how residents of our state could be harmed by a practitioner misrepresenting themselves as a Genetic Counselor and providing genetic counseling without the proper certification from the American Board of Genetic Counselors. A lack of licensure in Wisconsin means there is no legal standard for who can call themselves a Genetic Counselor. Passing this bill will ensure minimum standards for academic background, clinical experience and skills necessary to deliver genetic counseling services.

As the knowledge of genetics and genomics rapidly expanded in recent years, Gundersen genetic counselors have assisted patients and healthcare providers throughout our system to translate genetic data and understand the implications of genetic testing results.

We provide current and accurate information about genetic testing options for hereditary health conditions. For those families with a preexisting hereditary condition, we are uniquely educated and trained to provide health information in a way families can understand. We are also ideally aligned in the healthcare system to provide support and advocacy for the patient and their family, as well as assist them with care coordination of screening or management options.

Gundersen currently employs four genetic counselors in multiple departments including Oncology, Pediatrics and Obstetrics. Each year, we support approximately 2,000 families as they navigate the complexities of genetic testing and diagnosis. Our system includes a primary hospital in La Crosse, five critical access hospitals and over 65 clinics throughout the Upper Midwest. We are committed to supporting public policy to enrich every life through improved community health, outstanding experience of care, and decreased cost burden.

We believe licensure for genetic counselors is important to ensure Genetic Counselors have appropriate training and credentials as genetic testing opportunities expand. We are pleased by the definition of who is qualified as a genetic counselor included in Senate Bill 620; this reassures community members and patients they are being assisted by qualified and certified genetic counselors who have undergone specialized education and training to provide care.

On behalf of Gundersen Health System and the Wisconsin Genetic Counselors Association, we are pleased to support Senate Bill 620. We look forward to advancing genetic counselor services within the healthcare community and will continue to support efforts made to further ensure care is available close to home.

Thank you for taking time to hear my testimony; I am happy to answer any questions.

Becky Pabst, MS, CGC
Lead Genetic Counselor
Genetic Services
Gundersen Health System



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1/28/2020

Dear Chairperson, Vice Chairperson and distinguished Members,

My name is Humberto Vidaillet. I am a medical doctor board certified in internal medicine, cardiovascular disease and clinical cardiac electrophysiology. As a cardiologist, I support Senate Bill 620, which would provide licensure for genetic counselors in Wisconsin. Christina Zaleski will provide you with testimony that I wholeheartedly support.

Genetic counselors play a critical role within my practice and provide information and support to individuals and families affected by, and concerned about, risk of genetic disorders.

The availability of genetic and genomic testing services is rapidly growing. Genetic counselors are ideally suited to work with cardiologists to deliver high quality, up-to-date genomics services and to ensure that patients using these services are adequately informed. Genetic counselors are vital collaborators in my practice.

Genetic counselors' expertise enables them to provide services that are cost-effective by ordering the right test for the right person. Many healthcare providers, who are not trained in genetics, request unnecessary or incorrect tests, which significantly increases healthcare costs.

Clinicians and patients need to know that the genetic counselors that they work with are adequately trained and up-to-date on genomic information.

As the field of medical genetics grows, so too does the need to provide the citizens of Wisconsin with accurate information regarding their genetic conditions, genetic risks, and results of genetic tests. No mechanism currently exists to ensure that the individual providing genetic counseling to citizens of Wisconsin is qualified to do so. In a climate where direct-to-consumer genetic testing is available and the complexity of genomic tests is increasing, the citizens of Wisconsin need to have access to professionals who have been deemed qualified by the state.

I hope that the committee will work with Wisconsin Genetic Counselor Association to enact genetic counseling licensure to ensure that the citizens of Wisconsin receive quality genetic counselor services. I thank the Chairman and this committee for your attention to this important issue.

Sincerely,

A handwritten signature in black ink, appearing to read "H. Vidaillet".

Humberto J. Vidaillet Jr. MD, FACP, FACC, FHRS
Cardiologist, Electrophysiologist



TO: Honorable Members of the Senate Committee on Health and Human Services

FROM: Kendra Eaves, MS, CGC
Manager, Genetic Counseling
Medical College of Wisconsin

DATE: January 29, 2020

RE: Please Support Senate Bill 620: The Regulation and Licensure of Genetic Counselors

The Medical College of Wisconsin (MCW) respectfully requests your support for Senate Bill 620 (SB 620), legislation to create licensure and regulation for genetic counselors. Genetic counselors are healthcare professionals specializing in medical genetics and counseling. Currently in Wisconsin, there is no licensure requirement for those practicing genetic counseling. As a rapidly growing area of care, MCW believes Wisconsin should align our state's licensure laws with the 29 other states which have already enacted licensure for these healthcare practitioners. By doing so, patients may rest assured that these critical services are being delivered appropriately and with a high-level standard of care.

MCW currently employs 21 genetic counselors, who see over 5,000 patients annually at Children's Wisconsin and Froedtert Health clinics. MCW is also developing a Master of Science graduate program to train the next generation of genetic counselors in Wisconsin. As personalized and precision medicine becomes more prominent and critical for patient outcomes, MCW anticipates a dramatic increase in the need for genetic counselors within nearly all areas of medicine.

Genetic counselors enhance the physician-led care team by investing significant time and resources dialoging and assisting patients and their loved-ones. Key services provided include:

- Discussing and analyzing medical history and family history
- Explaining genetics, inheritance, and specific conditions in an easily understandable manner
- Reviewing testing options, ordering genetic tests as appropriate and personalized interpretation of genetic test results
- Providing psychosocial and supportive counseling

Genetic counselors hold Master's degrees in Genetics or Genetic Counseling, and are certified by the American Board of Genetic Counseling. Approximately 100 genetic counselors with this advanced training are currently practicing in Wisconsin. I want to highlight the importance of the existing national accreditation of genetic counseling training programs through the Accreditation Council for Genetic Counseling. Certified genetic counselors graduate from accredited training programs which ensure quality and educational standards are met for the profession. The genetic counselor Practice Based Competencies provide the guidance for the training of genetic counselors and an assessment for maintenance of competency of practicing genetic counselors. The competencies are categorized in the following domains: (I) Genetics Expertise and Analysis; (II) Interpersonal, Psychosocial and Counseling Skills; (III) Education; and (IV) Professional Development & Practice.



SB 620 will protect the public, ensuring there is a legal standard for those representing themselves as genetic counselors, while also ensuring individuals and families receive the highest-quality services. The legislation will also provide the public with a means to identify whether a provider is a licensed and qualified genetic counselor and help ensure broad public access to these services throughout Wisconsin.

Finally, this legislation does not preclude other practitioners from providing genetic counseling if these activities are within their scope of practice and will align genetic counseling with licensure and regulation of other allied-health practitioners. Thank you for your time and attention.

MCW respectfully requests your support for SB 620. If you have any questions or need additional information following the conclusion of today's public hearing, please do not hesitate to contact Nathan Berken, MCW's Director of Government Relations, at 414.955.8588, or via email at nberken@mcw.edu.

**Senate Committee on Health and Human Services
Testimony provided by Peter Levonian, Director
Genetic Counseling Services at UW Health
January 29, 2020
RE: Support for Senate Bill 620**

Chairman Testin and members of the committee,

My name is Peter Levonian and I am a board-certified genetic counselor and Director of Genetic Counseling Services at UW Health. Thank you for this opportunity to appear before you today to express our support for Senate Bill 620 related to licensure for genetic counselors.

UW Health and our partners provide genetic counseling to well over 2,000 Wisconsinites each year. We see patients and families across the lifespan from preconception to adult-onset genetic conditions. We have a team of highly trained board-certified genetic counselors who see patients in multiple disciplines including pediatric genetics, oncology, obstetrics, adult and pediatric cardiology, and adult and pediatric neurology. We partner with our new Center for Human Genomics and Precision Medicine and together we provide exemplary genetic counseling care in a manner that supports patients and families at times of great stress.

I have been a board-certified genetic counselor for nearly 30 years and 25 years ago, the nine genetic counselors in Wisconsin at the time came together for a meeting in February. I still have the minutes from that meeting in 1994 and even then, we were focused on licensure for genetic counselors so the public would be able to identify who was qualified to help them navigate the complex genetic terrain. As I reflect on that discussion now, it is almost comical how naïve and understated our assessment of “complex” was all those years ago. In fact, it becomes vastly more complex every year and the potential for harm grows correspondingly.

Two years ago, I saw a 36-year-old woman who had just had both breasts and both ovaries removed surgically because a non-genetic counselor/non-MD provider told her that her genetic test results showed that she was at high risk for developing breast and ovarian cancer. She did not have pre-test genetic counseling, nor did she have a genetic counselor review her genetic test results prior to proceeding with these irreversible surgeries. Had she had access to a qualified genetic counselor, she would have learned that her “mutation” was not a mutation at all, but rather a subtle change in her DNA code that was likely just a harmless difference from one human being to the next. You may ask, “Why didn’t she seek a second opinion?” Unfortunately, she trusted the individual who gave her incorrect counsel because she had no way of identifying who was qualified to practice genetic counseling.

We must give patients and families a tool to help identify who is qualified to guide them through significant health care decisions like the patient I referenced. The potential harm to the public from inadequately trained (if well-intentioned) individuals is enormous and life-altering. It is for this reason that I hope you see fit to support Senate Bill 620.

Thank you for your consideration. I’d be happy to take questions at this time.