



Highlighting 2023 DEIJ Committee Accomplishments & Future Goals | 1
President's Perspective: Building Trust Together | 2
Meet Christie Hoell, New ABGC Board Member | 3
ABGC Board Update / Earning the CGC Credential | 4
Where Are They Now? Updates From ABGC Research Grant Recipients | 5

Highlighting 2023 DEIJ Committee Accomplishments & Future Goals

Featuring **Josie Baker, MS, CGC**, and **Whitney Neufeld-Kaiser, MS, CGC**

The ABGC Diversity, Equity, Inclusion and Justice (DEIJ) Committee has made exciting strides for ABGC Diplomates and the genetic counseling industry in 2023, and we can't wait to see what's in store for next year. In this article, two committee members — Josie Baker, MS, CGC, a cancer genetic counselor and assistant professor and Whitney Neufeld-Kaiser, MS, CGC, a laboratory genetic counselor — share details on some of their 2023 accomplishments.

These accomplishments include:

- Adding demographic questions to the certification exam to track trends that could inform future exam revisions, with the goal of increasing test equity.
- Creating a glossary of terms that will inform Diplomates on DEIJ terminology.

What made you interested in joining the committee and what is your role on the committee?

Josie Baker: Throughout my career, education and personal life, I have witnessed and experienced first-hand the barriers and discrimination that minority groups face. These experiences highlighted the disparities in health care and made me passion-driven to continually advocate for underrepresented communities. I was excited to bring my personal experiences and education to ABGC, in hopes of helping the organization grow as we learn together. I am thankful to work beside many individuals in the ABGC DEIJ Committee, who are dedicated to change and growth.

Whitney Neufeld-Kaiser: I'm one of the at-large members of the ABGC DEIJ Committee.

I was in on the ground floor of creating the Genetic Counseling Graduate Program at the University of Washington, where we had an exquisite opportunity to put anti-racist, equitable, inclusive policies and procedures into place to attract and support a diverse group of genetic counseling students. I learned so much from my BIPOC colleagues who also engaged in that process at the UW, and I was excited to bring the lessons I learned to ABGC.



Josie Baker, MS, CGC



Whitney Neufeld-Kaiser, MS, CGC

Can you share about the change to request demographic data on the certification exam?

Both: The genetic counseling profession is not as diverse as the patient population we work with. There are many reasons for this, and one might be that performance on the CGC exam is influenced by demographic characteristics. But since demographics have not been collected from exam applicants in the past, we have no data with which to evaluate this. The ABGC DEIJ Committee talked over several meetings about what demographics to ask for, when to ask for them and how to ask the questions.



We took inspiration from demographics questions in the NSGC Professional Status Survey (PSS) and recommendations from the Minority Genetic Professionals Network (MGPN). The end goal is to mitigate as much bias from the exam development process as possible.

The ABGC Board reviewed our draft language and sent back comments and suggestions to consider in creating the final questions and answer choices. We took inspiration from demographics questions in the NSGC Professional Status Survey (PSS) and recommendations from the Minority Genetic Professionals Network (MGPN). The end goal is to mitigate as much bias from the exam development process as possible.

Can you tell us about your experience on the glossary of terms subgroup? What was this group's goal and what has it accomplished?

Both: The DEIJ Committee has recognized the need to further bring awareness to DEIJ topics, leading us to create the first version of a glossary of terms. The developed glossary will include DEIJ terminology and definitions, as

well as examples to further aid in understanding of terms. Our goal is to aid ABGC and their committees, diplomates and candidates in effectively and appropriately understanding terminology that directly relates to diversity, equity, inclusion and justice. The glossary serves as a basic framework of terminology and examples to promote discussions surrounding DEIJ topics. The glossary will be updated throughout time to reflect the expansion and understanding of DEIJ.

Are there any other initiatives or successes you'd like to share about your time on the committee?

Both: Each member of the DEIJ Committee brings unique perspectives and lived experiences to the committee's work. It's an honor to continue to learn from our colleagues and to be a part of ABGC's very first DEIJ Committee. We've tackled some large projects that have largely been successful, thanks to both the dedication of the folks on the committee and the support of the ABGC board and staff. ○

President's Perspective: Building Trust Together

As my year as ABGC Board president ends, I am taking time to reflect on my term and thank those who served before me and who will serve after me. I've been incredibly grateful to serve this year, and particularly wish to thank previous Board leaders who helped identify needed changes as we transitioned management companies to Smithbucklin in 2023. This was the right decision to set ABGC on a path toward growth and improvement. I'm particularly grateful for all ABGC staff members, especially our executive director, Heather Rich, who have supported the board this year, devoting countless hours to Diplomates and candidates alike.

I know this year has been unprecedented, and I have heard and recognize the anger and frustration so many have had with the 2023 exam delivery. I am sorry for these terrible experiences. Please know that we

expect better from our exam delivery and exam delivery partners. I hope all Diplomates also know that the ABGC Board is made up of fellow genetic counselors who are committed to the profession and to the goal of advancing the value of genetic counseling — and improving the lives of our patients and their families. We will work diligently to find solutions for and build trust among Diplomates in 2024 and beyond.

As I move into the ABGC Board past-president position, I am glad ABGC is in a financial position to select a new exam vendor, who we have high expectations for delivering an exam process worthy of our profession. I look forward to assisting with the Board's next stage of strategic planning as well as supporting Angela Trepanier, MS, CGC, as she steps into the well-deserved role of president. I hope everyone will join me in welcoming her to this position.



Sarah Jane Noblin, MS, CGC

Again, thanks to all Diplomates for their understanding during this unprecedented year. ○

Sincerely,

Sarah Jane Noblin, MS, CGC
President, American Board of
Genetic Counseling

'If You Want Change, Be Part of That Change': Meet Christie Hoell, New ABGC Board Member

Christie Hoell, MS, CGC, is ABGC's most recent addition to the board of directors. She currently works as a senior graduate program educator at the Northwestern Graduate Program in Genetic Counseling. We asked her questions about her career so Diplomates can get to know her as well as her goals as she begins her service on the board.

ABGC: Could you share how your background has led you to this role as a board member?

Christie Hoell (CH): I have held several different leadership positions over the years. I was president of the Illinois Society of Genetic Professionals, and I've been active in NSGC, serving as chair of the Membership Committee and the Professional Status Survey. I felt like I had a lot of great experiences that I could contribute to ABGC. I also am a part of a program working with students, which gives me really valuable experience and insight to contribute to this role.

I tell my students, 'If you want change, try to be part of that change.'

ABGC: What inspired you to become involved with ABGC, and what excites you most about this new role?

CH: I tell my students, 'If you want change, try to be part of that change. Try to do things within your power to change.' There are a lot of great opportunities for ABGC to provide more services to Diplomates, whether that be exam resources for candidates or certification resources for Diplomates. I think there are a lot of great opportunities — and there are a lot of changes happening. I think it's a great time within ABGC to continue that strategic growth.

ABGC: Can you describe a significant moment or experience in your life or career that has influenced your passion for genetic counseling?

CH: What has shaped my career path is thinking about the impact of what I can do, whether that be in a clinic on an individual level with a patient, on an institutional level in a hospital or where I am now, in a graduate program influencing the next generation of genetic counselors. Thinking about that impact has fueled my career path as a genetic counselor.

ABGC: Do you have any role models or mentors who have had a profound impact on your journey in genetic counseling?

CH: There have definitely been people along the way who have helped me, and I'm very grateful for that. The people who have been most impactful for my career are those I've had the privilege of working alongside — my peers and colleagues who have inspired me to grow in many different ways. My students also keep me on my toes and hold me accountable. If you say you're going to do something, you had better do it. That's good and that's important, and I think they have pushed me beyond my comfort zone



Christie Hoell, MS, CGC

to take action when I was hesitating. That has made me grow.

ABGC: As a new board member, what are some specific goals or initiatives you hope to champion or contribute to during your tenure?

CH: A lot of great work has been done recently and is going to be implemented soon. For example, I'm excited for the DEIJ Committee to continue to build upon their work and I think there will be important conversations for how to navigate the changes associated with their work. [Read more on [page 1](#).] There is a lot we will be able to do with the data. Additionally, I'm looking forward to exploring the certification and recertification experience to identify gaps and opportunities and see what additional resources we can provide to candidates and diplomates, and how we can better communicate with our Diplomates as well. There are a lot of opportunities.

ABGC: What hobbies or interests do you have outside of work?

CH: With having two young kids, I am doing my best to carve out personal time. I love to read, love to try new restaurants in Chicago and love to travel — and hope to be able to get back to doing more of that in the near future. ○

ABGC Board Update: Planning for a Successful 2024

As we head into 2024, we wanted to share with our Diplomates that we, the ABGC Board of Directors, are committed to the genetic counseling profession and to ABGC's mission to establish standards of competence for certified genetic counselors and advance their value as leaders in precision health to safeguard and serve the public. We live out this mission through focus on core values — integrity, responsiveness, excellence and inclusivity.

We are looking forward to serving all Diplomates and candidates in 2024, to improving our service and to continuing to further the profession's value.

In 2023, issues with exam delivery made it clear ABGC missed the mark, and as certified genetic counselors ourselves who have all gone through the examination process, we hold that it is unacceptable for any of our candidates to face such issues with test delivery. These challenges have made it clear to us that our current exam delivery partner can

no longer effectively support us in upholding our mission or values.

As we have previously shared in mid-November, in order to deliver a successful exam process in the future, the Board is pleased to have signed a contract with Prometric to become our new test provider in 2024 and beyond. Prometric is a highly respected and trusted test provider that is used by hundreds of health care certification boards. We believe the transition to Prometric will provide a more seamless testing experience and will alleviate many of the issues experienced by test takers during the August 2023 exam window and in previous years.

To facilitate a smooth transition from PSI to Prometric, we will need to delay our Spring 2024 exam period from February to March. We recognize that waiting an additional 30 days to test may cause undue stress. However, we believe the delay is necessary to ensure an optimal testing experience, which is our top priority. Please visit our website to check for more details on upcoming test dates.

We are looking forward to serving all Diplomates and candidates in 2024, to improving our service and to continuing to further the profession's value. ○

Sincerely,
Your ABGC Board of Directors



**Sarah Jane Noblin,
MS, CGC**



**Angela Trepanier,
MS, CGC**



**Kate Wilson,
MS, CGC**



**Greg Ruf,
Public Member**



**Priyanka Ahimaz,
MS, CGC**



**Melanie Hardy,
MS, CGC**



**Barbara W. Harrison,
MS, CGC**



**Vivian Pan,
MS, CGC**

Earning the CGC Credential: 2023 by the Numbers

ABGC happily welcomed more than 400 new certified genetic counselors to our community in 2023, with a 68.5% average pass rate.

February Exam		
	Total Tested	Pass %
First Time	96	71.9%
Repeater	70	67.1%
Total	166	69.9%

August Exam		
	Total Tested	Pass %
First Time	399	69.9%
Repeater	46	43.5%
Total	445	67.2%

Where Are They Now? Updates From ABGC Research Grant Recipients

ABGC is honored to play a role in the transformative work done by genetic counselors by awarding yearly research grants to support their work. This article provides updates from a few of our recent grant recipients and the opportunities for further research they've discovered.

Research Project: Defining Macro-Level ELSI Knowledge and Competency in Genetic Counseling Practice, Research and Training



Year: 2022

Name: Shana Merrill, MS, LCGC

Background

Shana Merrill, MS, LCGC, developed the idea for

this research due to her interest in gaining a better understanding of systems-based aspects of genetic counseling practice and pragmatic conceptualizations of ELSI issues in genomic medicine. She is interested in better understanding what the profession defines as its core identity and functions as it evolves. More specifically, the idea for this research arose from considering the alignment between genetic counselors' Code of Ethics, Practice-Based Competencies and the expanded roles that genetic counselors may fulfill in the future, all within the context of applicable systems-based practice conceptualizations and ethical, social and legal frameworks that she was exposed to as part of her PhD studies in social welfare.

ELSI research and education in genetics have tended to focus on individual patient care-related issues and applications of general bioethics principles to specific cases. However, there is now widespread recognition in the field of the need for a diverse workforce to meet the needs of a diverse patient population, as well as the need to better understand systemic societal issues that impact the quality of health care provided and the profession's advocacy goals. This research seeks to eventually broaden conceptualizations of ELSI issues

in genetics to include more modern and nuanced understandings of current issues.

The goal of Shana's research is to translate these findings into education and training resources for genetic counselors, as well as apply the findings to the ongoing conversation about the scope of practice and core expertise of genetic counselors. This research fills the gap of exploratory, qualitative research in this field, as it is lacking. This topic is best studied qualitatively at this time, because, as participants often stated while conducting this research, genetics ELSI issues are complex and inextricably interwoven throughout all aspects of genetic counseling training, practice and professional identity in a wide variety of ways.

Findings

Shana's team conducted focus groups with stakeholders including genetic counseling program directors, experienced genetic counselors and recent graduates of genetic counseling programs. These focus groups elicited perspectives on critical contemporary ELSI concerns in clinical practice, genetic counseling role and identity relative to these issues and perspectives in interprofessional theoretical and practice grounding. They are currently analyzing verbatim transcripts of focus groups and conducting in-depth individual interviews with an expanded population of stakeholders, including academic researchers of ELSI topics in genetics, physicians with expertise in genetics ELSI and additional genetic counselors from a variety of backgrounds. The team envisions completing data collection and analysis by the end of 2023.

This research was designed to explore stakeholder perceptions of professional role identification and the necessary expertise to engage with genetics ELSI issues. It was designed to explore the extent to which genetics ELSI issues are experienced variably within large systems and intuitions (spaces conceptually known as macro and meso levels), in addition to at the point of care (conceptually known as micro level). One goal of this research was to obtain data to help identify and adapt relevant

and appropriate conceptual frameworks more specifically to genetic counseling contexts. In part, this research intends to address the question of whether genetic counseling training and competencies should expand to include additional consideration of the macro and meso-level dimensions of patient care and advocacy, or whether interprofessional partnerships and alliances will best serve in expanding the scope of ELSI endeavors in genomic medicine. Once the analysis and Shana's dissertation are complete, the findings will be prepared for consideration for publication in the Journal of Genetic Counseling.

Additional Insights

One aspect of conducting this research that surprised the research team is how often focus group participants articulated their enjoyment and intellectual gain from participating and hearing additional perspectives on pragmatic ELSI issues from others practicing in different geographic locations and/or job settings. Experienced genetic counselors felt as if they were lacking opportunities to have ongoing in-depth conversations about these topics. Another aspect the team has found surprising from this research is the extent to which very few genetic counseling stakeholders articulated that advocacy should be part of the core professional identity of all genetic counselors, while simultaneously articulating their recognition of advocacy's inclusion in the genetic counseling Code of Ethics.

Future Opportunities

The findings from this research project could be utilized to inform the design of a thorough and targeted quantitative research project to capture a larger sample of opinions from additional stakeholders. Future research could also evaluate current ELSI education across genetic counseling programs, test training tools and educational approaches developed from this data, and/or determine the best mechanism for diffusing those resources to genetic counselors. Shana is grateful for the ABGC funding mechanism that supported this research. It will form the foun-

dition of ongoing efforts to create robust evidence-based conceptualizations of ELSI issues that can hopefully inform the practice of modern clinical genomic counseling.

Research Project: Exploration of the Need for Additional Credentialing for Laboratory-based Genetic Counselors



Year: 2020

Name: Lisa Schwartz, EdD, MS, CGC

Background

Dr. Lisa Schwartz decided to conduct this research after she recognized increasing opportunities for genetic counselors to work in the laboratory setting and wondered if genetic counselors needed or wanted additional training to serve in these roles. Her department offers graduate-level courses in laboratory science — including techniques and management — and she wondered if there was interest among genetic counselors in this setting to pursue a post-master's certificate in laboratory science.

To conduct the research, she assembled a team of fellow genetic counselors working in laboratory settings and education to serve on the advisory board and used mixed methods to gather data. She first interviewed 20 genetic counselors regarding their participation and roles in the industry or in laboratory settings. Then, she created a quantitative study based on these findings that was sent to all ABGC Diplomates. Read more details about the study's goals [in an ABGC article from 2022](#).

Findings

The study found that, overall, genetic counselors in laboratory settings believed ABGC practice-based competencies (PBCs) were transferable to their roles, and their master's programs prepared them well for the work. Most did not wish to have an additional requirement or credential — such as a post-master's certificate — to serve in a lab role, as they were concerned this could limit opportunities to move into these roles. Most other skills genetic counselors needed they developed through on-the-job training, although they did note a need for more

Multiple participants referred to themselves as not providing “true” genetic counseling or feeling unable to refer to themselves as “genetic counselors.”

exposure to the diverse roles available in the laboratory setting and would like to see those explained in their programs, including how PBCs can translate into these roles.

This research adds to the growing body of literature regarding the rapidly evolving roles for genetic counselors in laboratory and non-direct patient care settings. The findings aligned with others who suggest that additional didactic coursework and fieldwork related to the lab setting should be incorporated into master's in genetic counseling programs, and that considerations should be made to allow for cases collected in these settings to be used towards eligibility for ABGC certification.

The qualitative phase of the study was presented at the NSGC 41st Annual Conference in Nashville and has been published in the *Journal of Genetic Counseling*, while the quantitative phase was presented as a poster at the NSGC 41st Annual Conference in Nashville. A manuscript focused on the quantitative survey has been submitted for consideration by the *Journal of Genetic Counseling* and is currently being revised before resubmission.

Future Opportunities

During the qualitative analysis of interviews, Dr. Schwartz and her team discovered a recurrent theme regarding professional identity. Multiple participants referred to themselves as not providing “true” genetic counseling or feeling unable to refer to themselves as “genetic counselors.” This finding was unexpected, and Dr. Schwartz and her advisory board as a result proposed a new study of professional identity among genetic counselors: *An Exploration of Genetic Counselors' Professional Identity*, which is being funded through the 2022 Jane Engelberg Memorial Fellowship within NSGC. Currently, Dr. Schwartz is conducting a scoping review of the genetic counseling literature regarding professional identity as well as interviews

with 50 Genetic counselors from diverse backgrounds, settings and roles.

Research Project: The Patient Experience and Psychological Response to Reflexive BRCA Tumor Genetic Testing



Year: 2020

Name: Jeanna McCuaig, MSc, PhD, CGC

Background

Recently, the province of Ontario, Canada implemented reflex *BRCA1/2* tumor testing for all newly diagnosed high-grade serous ovarian cancer (HGSOC), without prior counseling or patient consent. This was announced prior to the availability of any patient outcome data and without consultation with the wider genetics community and was a significant practice change in the care of high-grade serous ovarian cancer patients.

Considering the high proportion of germline *BRCA1/2* gene mutations that are identified in tumor tissue (compared to somatic), and the relatively high level of public awareness of the *BRCA1/2* genes (thank you, Angelina Jolie), Dr. McCuaig and her team thought it was important to gather patient outcome measures to ensure this model of care did not negatively impact patients. Additionally, the study was completed in the hope that results would guide additional research in this area and inform the implementation of reflex tumor genetic testing in other provinces and countries and for other disease sites.

To accomplish these goals, Dr. McCuaig conducted a patient survey study aimed at evaluating the experience of newly diagnosed high-grade serious ovarian cancer patients who received reflex *BRCA1/2* tumor genetic testing as part of their cancer care. The research was conducted as part of

Dr. McCuaig's PhD thesis at the University of Toronto and was completed at the University Health Network, with the addition of Sunnybrook Health Sciences Centre to increase recruitment. [Read more details about the study's goals in an ABGC article from 2022.](#)

Findings

Broadly, the results of this research highlight the importance of researchers, including genetic counselors, to collect patient-reported outcome measures when changing models of genetic service delivery. Such research is critical to ensuring that as genetic counselors increase access to timely genetic testing, they are also able to identify and provide necessary resources and supports to the patients they serve.

In a first analysis (PMID 35418215), Dr. McCuaig and her team found that ovarian cancer patients do not have a good understanding of tumor genetic testing. Among study participants, less than half could accurately recall their tumor test results. The mean score on hereditary knowledge questions was ~67% correct (out of 100%). Additionally, a new diagnosis of ovarian cancer is more distressing than receiving genetic test results. The average level of cancer-related distress in the study population of newly diagnosed ovarian cancer patients was relatively high; over half of the study cohort had at least a moderate level of cancer-related distress. Average measures of genetic testing-related distress were also higher than previously reported in the literature. Also, while cancer-related distress was associated with higher levels of genetic testing-related distress, higher levels of dispositional optimism seemed to provide a protective effect.

Despite having high levels of patient satisfaction with having reflex *BRCA1/2* tumor testing completed as part of their cancer care, the high levels of distress, low knowledge scores and poor recall of tumor results indicated that patients may benefit from additional support and educational resources.

In a second analysis, (PMID 36478486), Dr. McCuaig and team found that genetic testing-related distress following receipt of tumor genetic test results significantly decreased following receipt of germline genetic test results and post-test counseling. This result highlights the benefit of post-test counseling in streamlined genetic testing models of care where feasible. Unfortunately, the study population

was too small (n=52) to complete meaningful analysis on the impact of receiving discordant tumor and germline results. As an example, Dr. McCuaig explained, "I suspect that the experience of someone receiving a negative *BRCA1/2* tumor result and positive germline panel result (i.e., not eligible for targeted therapy but has a hereditary risk), and that of someone receiving a positive *BRCA1/2* tumor result and negative germline panel result (i.e., eligible for targeted therapy and has no hereditary cancer risk) would be very different." Because of this, Dr. McCuaig believes additional research on these type subgroups would help to identify which patients may benefit most from additional support and post-test genetic counseling.

Additional Insights

Dr. McCuaig and team captured open-ended responses (unpublished) which provided insight into the varied experiences of patients. Some were able to clearly articulate the impact of tumor testing on medical management and the requirement of additional testing to clarify germline risks, while others were unaware that any test was completed.

Additionally, their team learned that higher dispositional optimism was associated with lower genetic testing related distress — an interesting discovery. According to Dr. McCuaig, it is surprising that this measure (Life Orientation Test - Revised) is not used more widely in the genetics literature.

Future Opportunities

According to Dr. McCuaig, this study could be replicated at another institution; however, she believes additional qualitative work to gather an in-depth understanding of patient experiences related to reflex *BRCA* tumor testing may be of benefit.

As precision medicine continues to advance and more patient outcome research studies examine the impact of tumor genetic testing, there is a need to develop validated tools that are specific to the experience of *tumor* genetic test results. Many studies, including Dr. McCuaig's, use the Multidimensional Impact of Cancer Risk Assessment (MICRA) questionnaire to evaluate psychosocial outcomes; however, the measures on this questionnaire are more aligned to germline testing and do not accurately capture the nuances of tumor testing. ○

2023 BOARD OF DIRECTORS

Four-year terms begin January 1 and end December 31

PRESIDENT

Sarah Jane Noblin, MS, CGC

PRESIDENT-ELECT

Angela Trepanier, MS, CGC

SECRETARY/TREASURER

Kate Wilson, MS, CGC

PUBLIC ADVISOR

Greg Ruf

DIRECTORS

Priyanka Ahimaz, MS, CGC

Melanie Hardy, MS, CGC

Barbara W. Harrison, MS, CGC

Vivian Pan, MS, CGC

EXECUTIVE DIRECTOR

Heather Rich, MPA, ICE-CCP

MANAGING EDITOR

Juliana Ludema McPherron

ABGC Executive Office

330 North Wabash Ave.

Suite 2000

Chicago, IL 60611

info@ABGC.net

Get Social

Follow ABGC on social media

