



August 4, 2022

Dear NSGC members,

NSGC is in a time of great change. The genetic counseling profession is a close community, and the individuals who have reached out to the Board – through the “DNA Exchange” blog post and other avenues – are our valued colleagues, friends, and past leaders. All are or have been engaged NSGC members. We appreciate these voices at this new crossroads in the history of our profession.

NSGC is a not for-profit, volunteer-based professional organization with a specific mandate to support the education and professional development of genetic counselors. We, the current Board, are entrusted with the responsibility of setting the strategic direction of this organization, which greatly impacts the future of our profession. We take this responsibility seriously, and at times it requires us to make painful and unpopular tradeoffs. Responsibility for our organizational and professional success also rests with our staff, volunteers, and individual members. This shared responsibility involves taking a look at the past, seeing how it brought us to the present, and learning how we can each make things better for the future in our different roles. We can only aim to be successful by being open to expressing and receiving our different perspectives and experiences to and from one another.

It is in this spirit that we share this response and hope it will be received. While there are no easy answers or quick fixes to remedy many of the concerns, we are listening to you and we recognize the need to evolve together by building understanding.

In the response that follows, we offer three things:

- First, we acknowledge the major social and political developments that have changed the national landscape in which we and our patients live, such as the *Dobbs vs. Jackson Women’s Health Organization* Supreme Court ruling.
- Second, we outline factual information about our efforts to achieve Federal recognition by the Centers for Medicaid and Medicare Services (CMS). Relatedly, we describe some lesser-known strategies NSGC is pursuing to ensure the sustainability of our profession.
- Third, we provide our account of NSGC advocacy priorities and activities.

Acknowledging the Past

The genetic counseling field has a long history of advocating to be recognized for who we are and the value we bring to healthcare. Over the years, this has taken different forms set against varying societal, policy and political environments. An often overlooked and tough reality is that our power to influence any of our advocacy priorities is limited by how well-recognized and financially sustainable we are as a healthcare profession. Without recognition for our profession by CMS, accompanied by broad and consistent reimbursement for our services, our political capital remains relatively low among healthcare



professions. For this reason, and to ensure the economic sustainability of the clinical positions genetic counselors hold in medical centers, industry, and other settings, pursuing recognition from CMS has been NSGC's top priority for at least a decade.

At the same time, our profession has also recognized that autonomous prenatal decision-making and disability rights are central and equally important values we hold. At times, these foundational values have been politicized and falsely pitted against one another. In a similar vein, as the United States has grown more politically divided, it has been increasingly challenging to voice our commitment to reproductive freedom while also pursuing bipartisan support of our Federal bill. Given the current Congressional makeup, bipartisan support is required for the passage of our Federal bill. This tension has been acknowledged and re-evaluated by different Boards annually over the past decade. The *Dobbs vs. Jackson Women's Health Organization* Supreme Court ruling severely limited reproductive choices and access to safe prenatal care in the United States. We acknowledge that it presents us with the need to partner with NSGC members to re-evaluate the allocation of our available resources and political capital across different advocacy priorities. We must take into account the balance between the overarching ethical values that unite us and the realities that characterize today's political landscape.

While considering advocacy goals that are at times in tension with each other, we have upheld NSGC's mandate to "aid and encourage the development and growth of the profession of genetic counseling," at a time of great growth and change in the profession ([Heimler 1997](#)). The mounting resource needs of our organization have required us to realistically assess our ability to impact the strategic priorities, including the advocacy priorities, to which we commit our organizational resources. It is with this history and framing in mind that we now elaborate on some of the details of our federal advocacy efforts.

Federal Advocacy (~2007-2022): A Summary

Building the case for genetic counselor recognition

Genetic technologies and the integration of genetics into healthcare have far outpaced the systems for reimbursement and payment for genetic counseling services. Without coverage and reimbursement, community and private hospital systems throughout much of the US are making continual decisions not to hire genetic counselors ([Bellaiche et al. 2021](#)), Professional Status Survey Work Environment Report, pg 13). Our services are therefore provided most frequently to those who have the resources to pay for them, who get care at academic health medical centers, or through free counseling programs. NSGC has worked to support billing for services by obtaining CPT® code 96040, obtaining a telehealth modifier, and continuing to advocate for [better reimbursement of the current code](#) to make the case for better billing and reimbursement of genetic counseling services. Currently, 64 million Medicare beneficiaries lack access to genetic counseling simply because of their primary healthcare coverage. Payment decisions by private insurers often follow CMS guidelines for payments, further exacerbating this gap in access.

Legislative changes to Medicare policy take years, and sometimes decades to be enacted. The Genetic Information Nondiscrimination Act (GINA), for example, was introduced in 1995 and didn't pass until 2008 ([Timeline of the genetic information n...](#)). It took physician assistants from 1977, when they first were certified in rural health, to 2020 to obtain direct reimbursement of services and a similar level of recognition and reimbursement as our proposed legislation (85% of the physician fee scale) ([PA Profession Historical Milestones - AAPA](#)). Physician assistants had obtained licensure for their profession in all states as of 2000 and it still took 20+ years for the American Academy of Physician Assistants to pass a bill similar to ours .

Before genetic counselors could be considered by CMS to be added as recognized providers, the field needed to collect data to make our case to legislators. In 2007, NSGC and John Richardson, NSGC's Director of Government Relations, began lobbying for GINA and thus began our efforts to promote genetic counselors on the federal level. John has over 25 years of experience working on policy and legislative issues in Washington D.C. After five years of working on the Hill, one of his first clients was vision rehabilitation professionals. He was able to include them in a [Medicare demonstration project](#) that highlighted their importance in working with blind Americans.

From 2007 - 2017, NSGC maintained a presence on Capitol Hill and within the federal government. Work was put into addressing areas where data or research was missing to support our case for recognition by CMS, and engaging with politicians about our issues. Countless committee volunteer and Government Relations staff hours were put into workforce studies by NSGC to forecast the number of GCs needed to support the rising demand for genetic testing and genetic counseling services and to counteract the persistent dialogue around the shortage of genetic counselors. To support, augment and accelerate these efforts, NSGC engaged a health economics research firm and invested in research to demonstrate cost savings and effectiveness of our services. At the same time, our members worked with the support of John at the state level to drive genetic counselor scope of practice and licensure.

Shifting to active lobbying and other legislative efforts

Over time, NSGC accumulated the data to critically position ourselves to submit our case for CMS recognition. The process of drafting legislation started in 2017, with the first bill introduced at the end of 2018. NSGC hired an external lobbying firm, Capitol Counsel, to actively start efforts on the Hill in 2018. Capitol Counsel was hired to work hand-in-hand with our NSGC Government Relations team and NSGC members.

[Capitol Counsel](#) is a significant contributor to securing strong bipartisan support due to their deep relationships and excels in all aspects that were identified as being important in the petition. See the firm's team bios.

- The firm has an outstanding reputation in healthcare and partners have been involved in major healthcare policies that Congress has considered for the last 20-30 years. Some examples of other clients include providers such as physical therapists, dentists, community pharmacists,

ophthalmologists, dermatologists, emergency physicians, gastroenterologists, and psychiatrists. They also represent clients such as BIOGEN, Genentech, GSK, and March of Dimes.

- Two of Capitol Counsel's partners, [Jeff Carroll](#) and [Ann Jablon](#), who lobby on NSGC's behalf, are former Chiefs of Staff to key committees of jurisdiction for our bill: Jeff to House Energy and Commerce Committee Chairman Frank Pallone (D-NJ) and Ann to House Ways and Means Chairman Ritchie Neal (D-MA). The firm has several individuals that have served as senior staff to the Senate Finance Committee (another committee of jurisdiction for our bill) including a former Staff Director for the committee.
- The Capitol Counsel team has been directly involved in Medicare policy that was enacted over the last 15-30 years. Some examples include helping add nurse anesthetists as recognized Medicare providers, achieving Medicare coverage of diabetic retinopathy diagnostic testing in a primary care setting, and drafting statutory language and achieving enactment of the Medicare preventive colorectal cancer screening legislation on behalf of the American College of Gastroenterology.
- Another Capitol Counsel lobbyist, [Shannon Finley](#), has over 20 years of experience working on reproductive rights and serves as Planned Parenthood's chief outside lobbyist.

During the 2019-2020 legislative session, which was abruptly halted by the COVID-19 pandemic, the Board recognized that more involvement with our lobbying firm, better volunteer member coordination, and a structure to report and assess metrics were needed to support this federal effort.

Since the "DNA Exchange" post and petition are directed at a Request for Proposals (RFP) to assess a new lobbying firm, the Board's approach to selecting a lobbying firm is summarized here. In late 2020 / early 2021, the Board at that time sought to interview 2-3 firms, one of those being Capitol Counsel. Firms completed a questionnaire and made a presentation to the Board. The group that was not selected presented no substantive changes to our tactics, had arguably less expertise, and was double the cost. The Board discussed an approach to a White House strategy with Capitol Counsel and agreed to continue with them. While not an official RFP, our outreach, interview, assessment and decision-making followed a very similar process.

Harnessing the expertise and power of NSGC volunteers

In addition, the Board saw a need to engage more volunteers and created the Advocacy Coordinating Committee (ACC). The ACC is a group of volunteer NSGC members with experience or interest in advocacy that represent legislative districts across the US. ACC members actively communicate with NSGC members in their region about our advocacy strategy. ACC members also recruit members in key Congressional districts to meet with their Representatives and Senators with the support of our Government Relations staff and Capitol Counsel lobbying team. In 2021, the Board also instated regular review of Board-approved metrics to monitor the progress of our advocacy efforts. Some of the success metrics we track include, but are not limited to, the number of meetings with members of Congress per month, meetings held with prioritized members such as those on committees of



jurisdiction, number of new organizations engaged in supporting our bill, and number of genetic counselors participating in these efforts.

Current State of NSGC Advocacy Efforts (2022)

Federal bill advocacy efforts

That brings us to the present, a time in which federal advocacy efforts and strategy are occurring on multiple fronts. This year the ACC reorganized and with Congress returning to a pre-pandemic level of activity, we have been able to leverage the data we have collected, and maximize the coordinated volunteer, staff and lobbying team effort that we had built over prior years. This has led to substantial progress, far outpacing the previous year and hitting all major metrics that were outlined. The bill has been sponsored in both the Senate (S. 1450) and the House (H.R. 2144), and has far more cosponsors than in prior years (50+), with close to 50% being on committees of jurisdiction. This is due to the hard work of our Government Relations staff, Capitol Counsel, ACC, and NSGC members who have met with 100+ different Congressional offices already this year. For those wanting to be involved, you can sign-up to meet with your legislators, we have included a link [[sign up here](#)].

The NSGC Government Relations staff team worked with Capitol Counsel to hold a Congressional Briefing in July which included Board liaison to the ACC, Dr. Altovise Ewing, NHGRI Director, Dr. Eric Green, cancer genetic counselor and NSGC Treasurer/Secretary with Heather Hampel, and her former patient, Jay McDaniel. In addition, NSGC President Heather Zierhut was able to share that the ACC and our Government Relations staff team has garnered organizational support from over 300 organizations, many with importance to the cancer Moonshot and CMS. For a comprehensive overview of the importance of this bill, we suggest reviewing the [Congressional Briefing webpage](#).

One advocacy strategy is to find opportunities for our bill to be inserted into existing legislative vehicles being proposed to Congress. Genetic counselors were added to H.R. 6000 (CURES 2. 0) for the pharmacogenetics provision and broad support from NSGC's advocacy partners, such as the Personalized Medicine Coalition, helped with this. Capitol Counsel, NSGC's Government Relations staff team, and board member, Heather Hampel, successfully advocated for genetic counselors to be included in President Biden's Cancer Moonshot initiative, one of the only recommendations in the initiative that requires legislation to be implemented.

Additional Advocacy Efforts

NSGC's advocacy and government relations efforts go beyond CMS recognition. In discussions with the Public Policy Committee in anticipation of major legislative changes severely restricting abortion access and the ability of genetic counselors to practice, the 2021 Board decided it was time to dedicate volunteer expertise and efforts toward advocate for reproductive access, freedom and justice. Following an application process, the [Reproductive Access, Freedom and Justice Task Force](#) was convened in

2021. Their [charter](#) includes advancing the strategic objective of advocating for the ability of genetic counselors to practice and serve their patients impacted by these infringements on reproductive rights. Examples of completed activities include:

- Developing a list of resources and organizations that may enable and empower our members to support patients and address pending legislation on a local level
- Outlining where NSGC has a unique voice in supporting reproductive decision-making in the context of our organization's mission and values.
- Collaborating on various advocacy tools, communication strategies and resources, such as [ACMG, ASHG and NSGC's joint public statement following the Dobbs decision](#), NSGC's revised [Access to Reproductive Healthcare position statement](#)
- Shaping and hosting a recent [member webinar](#) on the Dobbs decision and its impact on genetic counselor practice, and media outreach following the Dobbs decision

Over the past year, NSGC has regularly consulted with Shannon Finley and the Capitol Counsel team to assess the changing landscape and provide our Board as well as our ACC with expertise on advocacy related to reproductive healthcare issues.

Advocacy for better billing and reimbursement of genetic counseling services

The Access and Service Delivery committee, in collaboration with our Government Relations staff team, led the effort to request CPT® code 96040 be added under the 95 modifier to allow billing of telehealth services. Recently they have focused on [re-evaluating the 96040 CPT® code](#), which has resulted in crafting an application to revise this code through the American Medical Association (AMA), the organization that administers CPT® codes.

Licensure for the majority of states

Five states enacted licensure in 2021, and in 2022 two states have been added to bring the total number to 35 states, up from one in 2001. Enacting licensure laws is often a real challenge and a time-consuming process involving many genetic counselor volunteers in that state, supported by our Government Relations staff.

NSGC has invested in developing model licensure language for genetic counselors to use when pursuing licensure in their state and has grant funds available to fund local lobbying support. Our Government Relations staff advises genetic counselors on development of the licensure application, consults on strategy with the genetic counselors, lobbyists and legislators in states and testifies at hearings when bills are considered by state legislatures (often repeatedly over many years). This is a major effort for both volunteers and staff, particularly when many states do not have large numbers of genetic counselors to work on the effort.



Every state is different; a few states have enjoyed success within a few years and others such as New York have toiled with licensure for 30 years and still have not achieved licensure. With the growth in the number of states with licensure, NSGC staff and volunteers in the Access and Service Delivery Committee have been assessing options for multi-state licensure for genetic counselors.

Support of committees

Accomplishing this large body of work requires ongoing time and dedication of volunteers and staff. The considerable amount of Government Relations staff time needed to support the Access and Service Delivery Committee, Public Policy Committee, Advocacy Coordinating Committee and Practice Guidelines Committee is included in the NSGC Government Relations budget, and has necessitated the involvement of multiple personnel including John Richardson, Jennifer Trotter, and Molly Giammarco, among others. The costs for the time and expertise of Capitol Counsel staff have not increased since contracting with the firm in 2018. The Board has approved increasing the level of Government Relations staff to support new committees and add additional staff to bolster timely execution on many of NSGC's strategic initiatives, including work to advance our Federal bill.

Looking to the Future

During the in-person Board meeting in early June of this year, the Board held an advocacy planning session under the assumption that the impending Supreme Court ruling would overturn *Roe v. Wade*. In those conversations, and [informed by metrics that we had prospectively set and tracked](#), we determined that 2022's advocacy and lobbying efforts had made unprecedented progress towards CMS recognition. This progress was the result of the combined efforts of our Government Relations team, lobbying partners, and newly-reorganized, volunteer-led Advocacy Coordinating Committee (ACC). Given this progress, we decided to continue to push hard on our current strategy at a critical juncture in this legislative session and not issue an RFP for a new lobbying firm at this time.

NSGC is navigating balancing a range of advocacy efforts

These conversations had a "yes, and" rather than an "either/or" sentiment, which acknowledged the tension of our multiple priorities to support members, patients, and the future sustainability of our profession. Our discussions in June also considered the likelihood of electoral turnover in Congress as a result of the forthcoming midterm election, and the downstream impact this may have on future prospects for passing the federal bill. Related to this, we discussed that our 2023 advocacy strategy will need to address the tools and resources we can provide for prenatal genetic counselors in states affected by abortion bans, and to advocate for them to be able to practice according to our Code of Ethics and provide unbiased, comprehensive prenatal care, including discussing the option of abortion. These two priorities need not be considered as strictly either/or choices if we can find ways to strategically identify opportunities for the highest impact on an ongoing basis. We recognized that by thinking of our advocacy priorities as mutually exclusive, zero-sum efforts, we are limiting our potential.

Here are building blocks of the approaches the Board proposed in the June meeting and are continuing to refine as this year's legislative session draws to the end:

1. **Share an advocacy agenda beginning in 2023:**
 - a. Our advocacy agenda will outline the issues that we will be working on during each legislative session, and will propose a framework for identification of advocacy priorities.
 - b. Additional staff time and bandwidth will be needed to address the growing list of advocacy issues impacting our workforce, including our volunteer-led reproductive freedom, access and justice work. This capacity may come from new staff and/or may necessitate structural reorganization and streamlining or reprioritizing activity in other areas of NSGC.
2. **Conduct and report regular assessments of our advocacy metrics, resources and volunteer efforts:**
 - a. To do this, the Board will regularly review established metrics and every six months consider the level of investment in lobbying efforts, the status of our progress, and any changes or issues that need to be addressed in our strategy. This includes whether an RFP is warranted and whether we can absorb the transition costs of establishing new lobbying partnerships.
3. **Adopt a more flexible and nimble approach to advocacy strategy:**
 - a. As we have outlined, at times there are tensions between our different advocacy priorities, which can sometimes make it difficult and unwise to pursue all of them equally at the same time. We also do not have unlimited resources or bandwidth within the organization and are already operating at, or even beyond our current capacity. Some of what may externally appear to be inaction is actually an overwhelming of the system or a purposeful limiting of public information to avoid jeopardizing the overall advocacy strategy.
 - b. We have outgrown many of our current institutional structures and staffing models. Currently, our Executive Director, Meghan Carey, our senior staff, and our volunteer leadership are taking on the overflow. This is not sustainable for us or beneficial to the organization. To address this, we recently approved an external, global review of our organizational structure. This review will inform allocation of volunteer and staff advocacy roles and efforts and provide us with a multi-year plan to operate most effectively to meet our strategic goals.
4. **Foster inclusive public discourse about NSGC's advocacy approach**
 - a. As our organization grows and changes in shape, there will continue to be issues about which members will disagree. Future Boards may adopt differences in strategy from previous or current leadership. It may never be possible to fully satisfy advocacy needs that matter to our members, especially as our organization continues to grow and diversify. What we can commit to is promoting healthy dialogue about these issues between NSGC leadership, volunteers, staff and membership.



We celebrate the hard work of our Access and Service Delivery Committee, Advocacy Coordinating Committee, Reproductive Access, Freedom and Justice Task Force, Public Policy Committee, Prenatal SIG, NSGC members, Government Relations staff, and our Capitol Counsel lobbying team. Advocacy includes multi-year efforts involving organizational and individual member responsibility – not only current leaders but new ones, some of whom may be petition signatories that will help to “build the plane while flying it.” For those wanting to be involved, you can sign-up to meet with your legislators, we have included a link [\[sign up here\]](#).

An advocacy agenda could provide a means for deliberate and goal-driven collaboration with state-level genetic counseling societies and our partner organizations, all of whom share responsibility for the future of our profession with NSGC. In focused, dynamic and interactive ways, we can have open, respectful discussions about hard topics about which we may disagree. We can continue to see each other’s’ humanity, imperfections and shared values with compassion and understanding.

Sincerely,

The NSGC Board of Directors