

# National Society of Genetic Counselors

## **Policy on NSGC Position Statements**

NSGC Position Statements publicly convey the Society's unique views or opinions on issues of expert relevance to the genetic counseling profession. In some instances, a joint statement will be generated between NSGC and an outside organization with a shared interest. The statement may not coincide with the personal beliefs of each member, but provides a position based on the common interest shared among all members as professional genetic counselors.

### **Authorship**

All authors must release their copyrights to NSGC. No names will be associated with the statement since the statement reflects the collective view of the membership. Task force members may be acknowledged (on a case-by-case basis) with their permission.

### **Authorization of New Statements**

All suggested position statements topics should be submitted to the Public Policy Committee (PPC). The Committee or a Committee Task Force, which will consist of PPC member(s) and (as needed) members-at-large with expertise/interest in the issue or topic, will assess the need for a statement. At least one member of the task force must be a PPC member to serve as task force coordinator. The PPC will present its recommendation for a new position statement to the NSGC Board for approval. If the Board approves the recommendation to develop an official NSGC statement, the PPC will convene a task force, if one has not already been formed. In the case of joint statements, the PPC will collaborate with representatives of the outside organization to compose the statement.

Position statements should be limited in quantity to those of greatest need and impact. The following qualities should be used to evaluate the necessity of a position statement. Not all qualities are required for any given topic.

- The statement will endure for a significant period
- The genetic counseling voice offers a unique perspective on the topic
- The topic threatens the profession or is of potential harm to patients and the public
- The topic cannot be resolved through the straight-forward application of genetic counseling principles (e.g. gene patenting)
- The topic is of interest to the public
- The topic relates to the strategic plan.

### **Reviewing Existing statements**

The PPC shall review all NSGC Position Statements on every three years. An existing statement may be reviewed out of cycle as necessary. The task force reviewing an existing statement will recommend one of three decisions to the Board:

**Reaffirm existing statement:** NSGC may reaffirm the current statement if it still accurately reflects the views of the organization.

**Revise existing statement:** NSGC may revise an existing statement if the views of the profession have changed or new data affects the statement.

**Retire a statement:** NSGC may retire a statement if it is out of date or no longer applicable. NSGC archives all retired statements and places them under a section entitled "retired" on the NSGC website.

The PPC/task force makes a preliminary recommendation to the Board to reaffirm, revise, or retire a statement. In some instances, the task force may seek the opinion of the larger PPC, the original task force that created the statement, and/or, if necessary, create a new task force to make this determination. If the Board approves the recommendation to revise an existing statement, a task force will be assembled— if not already determined during the evaluation phase. If the PPC deems it appropriate/feasible, the authors of the original statement will be invited to help revise the statement. At least one member of the PPC will participate as coordinator and serve as liaison to the Committee.

It is possible that some statements may be combined if a revised statement becomes broader and more encompassing. The PPC also has the discretion to consider other alternatives if a task force deems appropriate.

### **Timeline and Volume**

The PPC may review or generate a maximum of three NSGC statements at one time. If prioritization becomes necessary, the Board will provide that direction.

The PPC/task force will send the final outcome (e.g. a new statement or a revised statement) to the Board for final approval.

### **Guidelines for Writing/Revising Statements**

- A strong statement is only a few sentences long. The public should be able to instantly identify the organization's position and its unique view on the issue when reading the statement.
- The statement should be concise, but NSGC may choose to release a more detailed background paper in conjunction with the statement to detail the rationale behind the organization's position.
- The statement does not need to speak for the personal views of every member of the organization. The statement is that of the organization, and may not satisfy every member when viewed from a personal perspective.
- Authors should look to the NSGC Code of Ethics when forming a position statement. Focusing on how the position statement applies to the conduct and views of genetic counselors as outlined in the Code of Ethics will help the task force focus on the positions that speak on behalf of the organization, not individuals.
- The statement should reflect the ***unique perspective*** of the genetic counseling profession to the issue/topic.
- Once task force members consider all possible positions that NSGC can take on an issue, they must determine which aspects most accurately reflect the NSGC's unique expert view. Even if NSGC could logically support several views, the statement should focus on the most appropriate position that NSGC can take based on common expertise. Questions that may assist with this process include:
  - Why does NSGC need this Position Statement?
  - How does this issue affect our profession?
  - Are there current misconceptions about our practice or view related to this issue?
  - What is the potential influence of the Position Statement?
  - What are all the relevant facets of the issue?
  - What controversies over this topic exist and why?
  - What is unique about the genetic counseling perspective to this issue?
  - How does our expertise factor into this issue?
  - What should be included in the scope of the issue?
  - Is there common ground from which to work?
  - What has been written about this issue, especially related to our perspective?
  - What current or pending public policy decisions exist related to this Position Statement?

- After evaluating complexities associated with an issue in accordance with NSGC's mission and goals, the task force may determine that NSGC does not need a statement, or that it is not possible to form a solid position at that time. The task force will submit the rationale for this conclusion to the Board. If the Board does not agree with this conclusion, the authors will have another opportunity to complete a draft or another work group will be assembled.

### **Review of Statements**

Once the draft meets the satisfaction of the task force, the PPC will provide feedback. The task force will consider the Committee's feedback and then send the statement, along with the rationale (if relevant) to the Board for preliminary review. The statement may go back and forth between the task force and the Board multiple times during the drafting and review processes.

Once the Board is satisfied with the statement and any accompanying rationale, the statement is disseminated to the membership for review. The NSGC membership will have a minimum of two weeks to provide feedback. The draft may also be sent to the appropriate representatives of ASHG, ACMG, ISONG, and other professional organizations identified as appropriate.

The task force will then review all member comments, make appropriate changes, and deliver the final statement to the Board for approval. The statement may go back and forth between the PPC, task force, and Board multiple times during the drafting and review processes. Once this occurs, the Board will determine if changes made based on member feedback necessitate further member comment. If so, the above process occurs until a final draft is achieved.

Once the Board votes to approve the final position statement and any accompanying rationale, the statement is disseminated to the membership via e-blast, Perspectives, and/or the President's weekly update. Joint position statements will be published as agreed upon by the joint organizations. The statement may also be publicized in other media sources. Finalized statements or their summaries and complete references will be available on the NSGC website.

### **Endorsing External Public Policy Statements**

NSGC may consider an outside position statement that an NSGC member, Committee, Special Interest Group, or the Board identifies for official NSGC endorsement. Like-minded organizations may request that NSGC endorse a public policy statement they have approved. Statements for potential endorsement should be submitted to the NSGC Executive Office, which will refer them to the PPC. For rigorous expert review, the PPC shall appoint an advisory committee of at least three NSGC members with expertise in the field that the statement addresses. The advisory committee will make endorsement recommendations to the PPC, which will forward them to the Board for approval.