American Society of Hematology Recommendations to the NIH’s RFI on Diversity, Equity, and Inclusion in Biomedical Research, Health Disparities and Equity Research and Workforce

The National Institutes of Health through this request for information, aims to identify approaches it can take to advance racial equity, diversity, and inclusion within all facets of the biomedical research workforce, and expand research to eliminate or lessen health disparities and inequities. Below are ASH’s recommendations in response to NIH’s request:

I. Perception and reputation of NIH as an organization, specifically as an employer (e.g., culture), with respect to support of workforce diversity and as an overall advocate for racial and gender equity in NIH-funded research
ASH commends the National Institutes of Health’s (NIH) sincere efforts to address various aspects of diversity, equity, and inclusion. The Society believes NIH could improve the organization's perception and reputation by:

- Partnering with organizations like ASH to advance anti-racism efforts within medical specialties.
- Supporting research on solutions to health care disparities.
- Transparently assessing and reporting on the perception among some investigators that NIH preferentially rewards scientists from privileged backgrounds and prestigious institutions.
- Creating a safe reporting process to address discrimination as it relates to race or gender for awardees of NIH funded grants.
- Increasing the visibility of women and underrepresented racial and ethnic groups in NIH leadership positions and study sections as well as among NIH award recipients.

II. New or existing influence, partnerships, or collaborations NIH could leverage to enhance its outreach and presence with regards to workforce diversity (both the internal NIH workforce and the NIH-funded biomedical research enterprise); including engagement with academic institutions that have shown a historical commitment to educating students from underrepresented groups, racial equity organizations, professional societies, or other federal agencies
ASH would welcome collaboration with the NIH to broaden the reach of the Society’s Minority Recruitment Initiative (i.e., expand additional trainees and junior faculty), a longitudinal pathway of career development award and mentorship programs to support and sustain interest in careers in biomedical research among medical students, residents, and fellows as well as graduate students and post-docs. While ASH has previously tried to engage NIH in broadening this effort, two barriers have seemed to prevent this: (1) ASH’s programs have an established track record compared to those of some other professional societies; and (2) hematology intersects with a number of institutes, including NIDDK, NHLBI, and NCI. ASH suggests a pooling of funds and centralized approach to working with professional societies – including those with strong track records – might help strengthen NIH ties to professional society efforts.
As part of its DEI efforts, ASH has long partnered with the Amos Medical Faculty Development Program (AMFDP), a mentorship and career develop award program with core funding from the Robert Wood Johnson Foundation. This program has helped numerous faculty from background underrepresented in medicine launch their careers and attain visible leadership positions in the biomedical research community, including several NIH institute directorships and the presidency of ASH. ASH’s financial commitment to the program to fund qualified hematology investigators beyond those supported by RWJF funds has yielded significant dividends, and qualified investigators continue to go without support due to budgetary limitations. NIH financial support for this program, currently directed by Dr. David Wilkes, would likely be quite welcome.

Due to its leadership in efforts to diversify the biomedical workforce, ASH is centrally positioned in a number of relatively new networks of professional societies that share this goal. The first of these networks is organized by the Council of Medical Specialty Societies and includes representatives of a number of physician organizations. The second network is organized by the Health Research Alliance, an organization of private funders of biomedical research, including professional societies and foundations. Both networks could serve as valuable partners with NIH in its diversity efforts. Please contact ASH Director of Awards and Diversity Patricia Frustace at pfrustace@hematology.org for more information.

III. Factors that present obstacles to training, mentoring, or career path (e.g., training environments) leading to underrepresentation of racial and ethnic groups (particularly Black/African Americans) in the biomedical research enterprise throughout the educational and career continuum and proposed solutions (novel or proven effective) to address them

The single largest barrier leading to “underrepresentation” of racial and ethnic groups in biomedical research is the inability or unwillingness of medical schools and graduate education programs to admit classes that, at a minimum, reflect the current diversity of the US population and that, ideally, aim to correct the overrepresentation, on a population basis, of certain populations in the research workforce. The allusions to legislative and legal restraints on NIH in this area are clear in the RFI. ASH welcomes the opportunity to understand these restraints from the perspective of NIH and to work with collaborators to address this core issue of the workforce pipeline.

For potential investigators in the pipeline, ASH believes the obstacles that impact their career paths begin very early. Below are specific examples of obstacles that the Society believes NIH should aim to address.

- Socioeconomic barriers impede underrepresented investigators and physicians from enrolling into schools or having access to resources that will make them competitive while also setting them up for success in the job market. The NIH should consider working closely with graduate and medical schools that serve underrepresented students to reduce financial barriers to careers in research.

- There is a limited number of mentors from underrepresented groups that can help foster the careers of the next generation of researchers and physicians. The few mentors that exist have huge demands on their time. The NIH should consider offering financial incentives (e.g., funding for administrative support) that will allow underrepresented faculty and mentors to have protected time dedicated to mentorship
of junior investigators. Furthermore, the institutes should offer resources and tools that will help all faculty be better mentors to trainees from underrepresented groups.

- Bias is also a key barrier to training and mentorship. NIH should invest in developing (and/or promoting existing) resources aimed at addressing implicit bias in medicine.

- Lack of a “safe space” for underrepresented groups to raise their concerns and to have them addressed is also a barrier. Such “safe spaces” could provide a forum for NIH and various academic institutions to learn more about the obstacles faced by underrepresented groups so that policies can be implemented and/or revised to address such obstacles. This will require: 1) NIH establishing its own “safe spaces” for underrepresented investigators at its institutes; 2) requiring that institutions with NIH funded grants create such spaces; and 3) having a team of trained individuals who can advocate for the needs underrepresented groups.

- NIH’s grant review process is perceived to be an obstacle in the career path of underrepresented groups. NIH should consider monitoring its current grant review processes to ensure fair grant reviews and consistent funding support that is central to a sustainable career in the biomedical sciences. Furthermore, ensuring that all NIH grant study sections have diverse representation of individuals will be vital to addressing this obstacle.

IV. Barriers inhibiting recruitment and hiring, promotion, retention and tenure, including the barriers scientists of underrepresented groups may face in gaining professional promotions, awards, and recognition for scientific or non-scientific contributions (e.g., mentoring, committees), and proven strategies or novel models to overcome and eliminate such barriers

The barriers inhibiting recruitment, retention, and promotion of underrepresented groups begin from having selection/hiring committees that do not reflect a diverse workforce. ASH believes that the following should be addressed to break these barriers:

- Ensure that selection committees tasked with hiring and/or promoting candidates include people from underrepresented groups.

- Make certain that anti-racist policies are adopted, implemented, and measured at the NIH and across academic institutions receiving NIH funding.

- Recognize both scientific and “non-traditional” accomplishments (i.e., committee service, advocacy, etc.) when evaluating progress and metrics for success.

- Providing more opportunities like the “Future Research Leaders” session hosted at the NIH’s research festival for underrepresented groups to present their research.

V. Successful actions NIH and other institutions and organizations are currently taking to improve representation, equity, and inclusion and/or reduce barriers within the internal NIH workforce and across the broader funded biomedical research enterprise

Included below are some actions that ASH is currently taking to improve representation and address barriers impeding the biomedical research enterprise:

- Through its Minority Recruitment Initiative, ASH addresses the underrepresentation of scholars in the field of hematology from diverse backgrounds by offering a two - four-year research awards to support historically disadvantaged physicians (MD/DO, PhD, and MD/DO-PhD) who are committed to developing careers in academic medicine and to serving as role models for students and faculty of similar backgrounds.
The Society would welcome the opportunity to work with ASH on expanding the number of opportunities available through this program.

- ASH’s Research Collaborative Sickle Cell Disease (SCD) Clinical Trial Network (CTN) is committed to having individuals living with SCD involved (early and in a meaningful way) in the design and execution of SCD clinical trials. To that end, the CTN is pursuing a robust community engagement strategy at both national and local levels to make sure trials conducted through the network meet the mandate of this community, mostly comprised of African American patients: “nothing for us without us.”

VI. Existing NIH policies, procedures, or practices that may perpetuate racial disparities/bias in application preparations/submissions, peer review, and funding, particularly for low resourced institutions, and proposed solutions to improve the NIH grant application process to consider diversity, inclusion, and equal opportunity to participate in research (e.g., access to application submission resources, changes to application submission instructions/guidance, interactions with and support from NIH staff during application process)

There is a perception that NIH's grant review process is not conducive to ensuring that grants from underrepresented applicants are appropriately considered. To address this perception:

- NIH should diversify the composition of its grant review panels. NIH could issue a request for applications to identify investigators from underrepresented groups who will be willing to participate in grant study sections. The NIH could also solicit assistance from professional societies like ASH that have access to a diverse pool of members who may be willing to serve in NIH’s study sections.
- NIH should require study section members to actively engage in anti-racism training.
- NIH should transparently assess and publicly report on the outcomes of the grant review process for underrepresented populations.
- NIH should engage an external organization to audit its grant review processes and procedures to identify additional areas for improvement.

VII. Best practices or proven approaches to build new or enhance existing partnerships and collaborations between investigators from research-intensive institutions and institutions that focus on under-resourced or underrepresented populations but have limited research resources

Two approaches that seem to build inter-institutional partnerships are as follows:

- In a number of career development programs both in the United States and around the globe, the Society engages in matching mentors with mentees across institutional boundaries. In a successful mentorship relationship, the mentee has an opportunity for exposures to different perspectives and skills, unfiltered input on career development, increased opportunity for exposure to other researchers, and the ability to tap into the mentor's resources. ASH matched mentors and mentees have gone onto to jointly publish research results and collaborate on projects; mentees’ careers have also blossomed through the development of new labs, national registries, and other research endeavors.
- In many clinical research studies, there are needs for patient data that outstrip the patient experiences of any given institution. Certainly, large consortia already exist to power clinical trials and allow investigators from across the many sites to contribute
to the work meaningfully and leverage the resources some institutions have in research cores, bioinformatics, and biorepositories. Similar collaborative approaches can also be implemented, on an ad hoc basis, to power smaller research efforts and leverage the data all sites can contribute as well as those unique resources only some sites can offer. For instance, ASH recently published online the results of a consensus among institutions as to the pathogenicity of common somatic mutations in hematological malignancies. This work would not have been possible without the contributions of both core research centers and institutions that contributed data and clinical perspectives.

VIII. Significant research gaps or barriers to expanding and advancing the science of health disparities/health inequities research and proposed approaches to address them, particularly those beyond additional funding (although comments could include discussion of distribution or focus of resources)
ASH believes the NIH will need to devote substantial resources to advance health disparities/inequities research. Below are some specific areas that the Society believes NIH should support to foster research and ultimately clinical care that is beneficial to diverse populations:

- Research aimed at understanding the impact of social determinants on health outcomes for patients with hematologic diseases is extremely vital. Such research could provide insight into therapy development as well as an understanding of why different patient populations respond differently to the same type of therapy.

- Increased efforts need to be made to include diversity and health disparities in preclinical discovery and translational science. Specifically, research addressing the correlation between genetic and environmental factors involved in the development of hematologic diseases should be funded since such epidemiological studies could further explain outcomes and survival patterns in patients with these diseases. In addition, support for the development of technological tools aimed at increasing diversity in genomic data is key to mitigating inequities.

- NIH should fund translational and clinical research that has direct impact on underrepresented communities. For instance, NIH’s support of the following research activities will go a long way at addressing health disparities:
  - clinical research done in rural communities
  - technology needed for trials engaging patients from rural communities

- In collaboration with the FDA, NIH should consider providing substantial incentives to encourage investigators to design clinical trials that will attract/enroll underrepresented patient populations. For example, incentives could be provided to investigators developing strategies to make innovative therapies (e.g., CAR-T cell and gene therapies) more accessible to underrepresented groups in clinical trials since such trials will be paramount to understanding the safety and efficacy of these therapies in different patient populations. In addition, the NIH should also aim to hold investigators of NIH funded clinical trials accountable when diverse groups are not enrolled.
IX. Additional ideas for bold, innovative initiatives, processes or data-driven approaches that could advance the diversity, inclusion, and equity of the biomedical research workforce and/or promote research on health disparities

Below are some additional ideas ASH recommends NIH consider:

- Advocating within the Department of Health and Human services and before Congress for policies that would ensure ongoing health insurance coverage for participants in clinical trials, particularly those that test novel therapies.
- Creating an inclusion index to measure the sense of belonging for underrepresented groups in research workplaces.
- Diversifying the face of the public representation of NIH.
- Supporting the activities of institutions that attract underrepresented groups into graduate and medical programs to strategically diversify and expand the biomedical research workforce pipeline.

Sincerely,

Martin Tallman, MD
President