

# The Public Interest Liaison Group's Contribution to the Future of Environmental Health Research

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It seems a rarity when a high-ranking official actually looks for public direction on the funding and programming he directs. Members of organizations of varying size often jockey for position, hoping to have the rare opportunity to bend the ear of such officials and discuss their thoughts on the direction that research should take on an important issue. For many organizations representing patients, health providers, and environmental advocates, Dr. Kenneth Olden eliminated the need to jockey for position by simply extending an invitation to be heard.

Several years ago, as head of the National Institute of Environmental Health Sciences (NIEHS), Dr. Olden added to his cache of public advisors by creating the Public Interest Liaison Group (PILG). This group comprises a cross-section of organizations interested in environmental health, and unlike the NIEHS Advisory Environmental Health Sciences Council, representatives are not required to undergo the scrutiny necessary in a federal advisory committee appointment. Further, in a true attempt to eliminate barriers to contributing to the future of NIEHS, the PILG was created in a manner that allowed the institute to fund meeting attendees' travel expenses. The creation of the PILG revolutionized how the NIEHS both interacts with the public and sets its research agenda.

At least once a year, Dr. Olden and his staff invite numerous organizations to meet over the course of 2 days. Additionally, numerous town-hall-style meetings are held around the country, allowing for an even broader level of participation. Organizations are given the opportunity to present information about their specific areas and research needs. The institute also provides presentations on the latest environmental health research funded by the agency. Most important, the meetings provide plenty of time for in-depth

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discussions among the organizations and the institute. Small, typically voiceless organizations are given equal audience. The PILG's composition includes large organizations represented by well-known advocate-researchers as well as organizations that are the creation of passionate advocate-patients affected by dreadful illnesses. The diversity among the participating organizations contributes to its uniqueness. Each organization is valued, respected, and fully included. Over time, organizations have found commonalities that have been the basis of independent projects and collaborations.

Dr. Olden is to be commended for using a new model for accepting public input into the research planning process. Although many federal agency heads attempt to create synergy between nongovernmental organizations and the agency, few go to the lengths he has to eliminate barriers to discussion. In the course of a few years, Dr. Olden and his staff have created a safe environment that welcomes discourse and includes even the smallest organization that otherwise would not have access to such high-level discussions. The result is the development of a community that is supportive of the institute and deeply involved in charting its future direction.

## Discussion

The creation and continuation of the PILG and similar relationship models have been and will continue to be important to the future of NIEHS for several reasons. First, its existence has created a broader pathway of dialog between the advocacy community and the institute. Second, the PILG has become an important vehicle for disseminating new research findings. Third, the PILG can be a significant collaborator in charting the

course of environmental health research as the institute undergoes new leadership. The PILG is a wonderful complement to all the more traditional, formal mechanisms of public contribution. Unlike the other forms, however, the PILG serves as a bridge to unite communities interested in environmental health research.

The advocacy community has long been a vocal advocate and critic of the National Institutes of Health (NIH). Hundreds of disease-oriented and professional health provider organizations have provided testimony and comments and routinely sought access to the leadership of NIH to offer research suggestions and challenges. Over the last decade, the advocacy community successfully pushed for doubling the NIH budget. With the dramatic increase in funding emerged in a far more open dialogue between the advocacy community and the NIH as the agency sought direction for the increased appropriations. Additionally, congressional and administrative oversight tightened to ensure that the public receives the highest return on the financial investment. Hundreds, if not thousands, of new research projects have been initiated with the new monies (Landers 2003), with substantial direction from the advocacy community.

Public engagement is critical to the operation of the federal government. At the agency level, private citizens and organizations are routinely invited to offer comments on proposed changes to regulation and research planning; the engagement methodology, however, is often too tedious and sometimes too laborious to ensure widespread participation. The perceived inefficiency not only discourages active participation but also breeds an element of distrust between advocates and those trying to help them through programming and research (National Public Radio 1999). This clearly

is counterproductive to encouraging public participation. Although the citizenry has long been supportive of the wide-ranging NIH research portfolio and actively engaged in its development, environmental health research uniquely lends itself to a broad cross-section of advocacy support. Entire communities galvanize around environmental health research as they seek empowerment, justice, and solutions to local health disparities. Lack of trust can be pervasive, and traditional interactions with the public agencies are not always successful. These larger communities of individuals, organizations, and health providers yearn for a different way of engaging with those setting the research agenda.

The PILG model stands out as a new paradigm for eliminating the negative relationship between NIH and its community. The PILG has allowed organizations once wary of interactions with the federal government to develop a more trusting relationship with researchers. This trust allows advocates and researchers to look beyond current research projects and build a future research portfolio that is progressive and forward thinking. For example, although children's environmental health advocates have worked closely with NIEHS to maintain support for the existing children's environmental health centers, the PILG relationship has allowed both communities to move beyond program maintenance and pursue the development of system/disease-specific centers such as those dealing with autism and asthma. PILG-style relationships maintain a sense of community, openness, and willingness to collaborate with the affected public.

That same public wants to know what the NIH and the NIEHS have done with the massive funding increases received during the last several years. Thousands of articles have been and will be published on new, exciting environmental health research. Communities want to know what researchers have learned. People want to know how this new information will affect treatment and the prevention of disease. And short of preventing disease, patients want to know if a cure has been discovered. Dissemination of information is very important to the advocacy community. Access to good information is demanded, and the ability to understand the information is critical.

Although the NIEHS, and the NIH in general, are adept at disseminating research findings through journals such as *Environmental Health Perspectives*

and through popular media, more detailed disease-specific research findings invariably may be lost in the shuffle of the wide range of news stories. Additionally, when accounting for the health literacy of the population—nearly half of Americans are unable to understand health information (Krisberg 2004)—it is easy to believe that many important research findings may be lost. Partnerships created through the PILG provide the institute with additional media outreach through affiliated organizations. Organizational newsletters, magazines, and web sites provide specific, detailed information to affected communities. PILG members find themselves in a unique position to translate research for their readers and explain what it means to them as patients.

For some PILG organizations, information dissemination is part and parcel of educating memberships. For some organizations such as the Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN), a professional nursing organization, including research findings in various publications is part of the organizational mission to provide professional development for its members. What remains special about the PILG relationship is the opportunity for its members to provide comments to NIEHS about the messaging around research issues. PILG encourages a back-and-forth dialog that educates both NIEHS and PILG organizations. For example, AWHONN is very concerned about how information is communicated to the public about how environmental health research is using breast milk as a biomonitor. The organization's participation in the PILG facilitates the organization's active encouragement of the institute to continue advocating breastfeeding as the optimal feeding choice of new parents despite confusing reports about the presence of toxic substances in breast milk.

The opportunity to provide specific information to their communities is an empowering element for some PILG members. As indicated previously, PILG member organizations are often populated by affected patients or their families. Some organizations have little or no scientific expertise within their membership. Organizations are able to use the relationships developed through the PILG to collaborate on information dissemination and even complementary research projects. Without the PILG "lynchpin," these opportunities cannot be maximized, affected patients might still be in the dark, and the NIEHS will not hear from a community that has something important to say about the research.

The PILG model also creates new research synergy between organizational researchers and the NIEHS. At a recent PILG meeting held 17–19 May 2004 in Greensboro, North Carolina, the Autism Society of America presented preliminary findings of a study conducted on mercury levels excreted through the hair of autistic children (Adams J, unpublished data). The conversation that followed included discussions on study replication and on implications for the future of autism research.

## Conclusion

Certainly other models like PILG exist as effective ways to include the public in charting the course of research. The NIEHS PILG does more than just engage its organizational members. Dr. Olden's PILG manages to harness the energy and passion of the environmental health community and channel it into meaningful, deliberative contributions to the future of NIEHS research while also creating synergy among organizations to creatively work together to advance their missions. Targeted research centers, new progressive research projects, and a unified advocacy community that translates and shares NIEHS information with a wide variety of communities are a lasting legacy for Dr. Olden. The PILG members appreciate his providing the community this important opportunity and look forward to continuing the efforts to expand and improve research at NIEHS in the future.

## SUMMARY

Several years ago, as head of the National Institute of Environmental Health Sciences (NIEHS), Dr. Kenneth Olden added to his cache of public advisors by creating the Public Interest Liaison Group (PILG). This group comprises a cross-section of organizations interested in environmental health that includes large organizations represented by well known advocate-researchers as well as organizations that are the creation of passionate advocate-patients affected by dreadful illnesses. The diversity among the participating organizations contributes to the PILG's uniqueness. Each organization is valued, respected, and fully included. The creation of the PILG revolutionized how the NIEHS both interacts with the public and sets its research agenda.

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## NOTES

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