

National Eye Institute VISION Public Information Network

Final Evaluation March 30, 2005





Communicating vision research to the public



Coordinated by the National Eye Institute National Institutes of Health U.S. Department of Health and Human Services

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I. PROJECT OVERVIEW

The National Institutes of Health's (NIH) National Eye Institute (NEI) is recognized throughout the world as a leader in vision research. The work of NEI and its grantee

institutions affects the medical community's response to preserving eye health and proper vision care, and has direct relevance on the well-being of families everywhere. But despite the expertise of NEI and its intramural and extramural research, communicating about any health care topic, including vision care, has become increasingly complicated. With non-stop broadcast news coverage, increased demands on national print newspapers and increased specialization of trade publications, it is increasingly difficult to coordinate messages across a wide group of interested parties to ensure that messages get the attention they deserve.

That's why leaders from NEI were wise to initiate an evaluation of its VISION Public Information Network (Network) at this time. After 10 years of support from NEI, the time was ripe to step back and evaluate whether the Network effectively:

- Enhances communications among professional colleagues working at diverse NEI grantee institutions
- Coordinates the dissemination of clinical research findings
- Builds relationships with media

• Ensures Network projects and issues get the attention they deserve

The VISION Public Information Network

The Network links public affairs professionals – mostly NEI grantees affiliated with eye institutes and departments of ophthalmology and schools and colleges of optometry – who communicate about vision research. Through Network activities, they share information, coordinate media activities and create opportunities for networking and professional development. Institutions that get involved in the Network appoint a public information specialist to work with NEI to participate in coordinated activities that help inform and educate the public about the benefits of vision research. Network members meet annually, share information through a listserv, pool resources to coordinate media outreach and collaborate on programs. The Network also helps inform the public of NIH's mission to improve the health of Americans through medical research.

Network Objectives:

- Develop strategies to maximize media coverage of vision research achievements
- Develop strategies to highlight the role of grantee institutions in conducting federally funded research
- Update Network members on NEI, NIH and DHHS activities
- Provide networking opportunities for public information officers
- Develop projects to inform the public about advances in vision research
- Inform the public about NIH's mission to improve the health of America through medical research

Evaluation Components

NEI engaged GYMR Public Relations, a Washington, DC-based communications firm that specializes in health issues, to conduct an in-depth evaluation of the VISION Public Information Network to confirm its value to NEI and its grantee institutions.

Goals of the Evaluation:

- Review offerings of NEI VISION Network
- Evaluate the Network's effectiveness at coordinating media relations among grantees
- Assess member satisfaction with the Network
- Generate ideas for possible new activities

To achieve these goals, GYMR conducted several core components of the evaluation process.

Evaluation Components:

- In-depth evaluation of Network materials
- Audit of approximately 250 media placements generated via Network activities
- Interviews with NEI staff, Network members and outside experts not affiliated with the Network
- Research into other comparable communications networks

Summary of Findings

The evaluation process was conducted over a period of four months (November 2004 – February 2005). GYMR worked closely with NEI communications staff and communications consultants currently contracted to NEI.

Findings from the evaluation process:

- NEI's VISION Network is unique and improves its members' professional abilities
- Network offerings are well-produced and well-utilized
- Media coverage of study results is well-coordinated and messages are consistent, due to the involvement of the Network
- For many powerful audiences at NIH and the Network members' institutions, the Network is a "best-kept secret"
- The Network's very diverse membership has interests in communications beyond media relations

II. REVIEW OF NETWORK MATERIALS

Background

To assess how the NEI VISION Network communicates with its members, GYMR examined various Network communications vehicles.

Network materials evaluated:

- Communication materials pertaining to clinical trial study results
- Network listserv communications
- Network Website (http://www.visionnetwork.nei.nih.gov) content
- Annual meeting materials
- Member surveys

The evaluation process provided insight into how effectively these materials communicate information to Network members and how closely these communications meet Network objectives.

Overarching Conclusions: Network Materials

Overall, materials disseminated by the Network to its members do help the VISION Network reach its objectives.

1. Clinical trial communications help individual grantee institutions maximize media coverage of NIH-sponsored research, while highlighting the institutions' role in the study. Press materials are thorough, varied and easy for Network members to use or pass on to others.

2. Listserv communications are frequent and cover many Network topics, including those related to NIH and DHHS activities. Interviews with Network members will later reveal that while listserv messages are considered one of the most useful Network offerings, this function is not fully utilized by members for networking and information sharing.

3. While annual meeting materials are comprehensive and informative, they do contain a lot of information that is difficult to review at a glance.

<u>A Closer Look: Communications Materials For Clinical Trial Study</u> <u>Announcements</u>

Questions considered when evaluating materials:

- How frequently do Network members receive information on clinical trials being conducted at NEI or grantee institutions?
- What is the Network's role in sharing this information?
- Are there opportunities being missed?
- How are media materials shared with Network participants?
- How frequently are they shared?
- What are Network participants asked to do with this information?
- How frequently do they take the desired action?

Evaluation Findings

1. Network members receive ample background information about each clinical trial. GYMR's review found that Network members receive clear and detailed information about trial results and suggested methods to distribute these results to local media outlets. Network members receive media dissemination tools including message boxes, advanced media materials, press releases and journal articles. Discussions with Network members indicated that institutions frequently utilize the information.

2. The media materials disseminated to participating institutions are

comprehensive and thorough. A news release, message box and backgrounder are distributed through the Network listserv for most clinical trials conducted. There does not appear to be a mechanism to currently track responses and/or feedback from participating institutions to evaluate the dissemination of media materials in local markets.

3. The method in which NEI distributes its messages is detailed and systematic.

A primary email regarding clinical trial information and advanced material requests are sent to the Network listserv, followed by a copy of the embargoed press release sent to participating institutions and/or interested Network members. This allows members to access advanced media materials and distribute them locally. Media coverage updates are also sent to the listserv after distribution of the press release, but NEI could consolidate these reports so members only receive one comprehensive update.

4. NEI requests that Network members keep Network staff informed of media results, although these requests are not consistent. In just two of the five clinical trials, NEI made a request that members forward any additional media coverage for tracking purposes. This is useful for NEI in compiling complete media coverage, but not asking for this information with every clinical trial limits the ability to compare results consistently.

5. Numerous emails are sent regarding communications for a trial. Prior to the distribution of a news release, two to three emails were sent to the listserv regarding advanced materials and clinical trial background information. Discussions with Network members revealed that these communications might be too frequent, and that some information could be better coordinated into one communication.

A Closer Look: Listserv Communications

Questions considered when evaluating listserv communications:

- How often are communications sent to participants?
- Do these communications help meet the Network's goals, or do they help achieve other goals that might not be cited?
- What type of information is being sent via listserv messages? Are Network members responsive to these messages?

Evaluation Findings

1. Participants receive frequent listserv announcements from the Network. GYMR's review showed that more than 175 email communications have been sent to the VISION Network listserv in the past year. This averaged more than three a week and was a significant increase over the previous year.

2. Listserv communications cover a range of topics and provide participants with opportunities to stay informed. Many topic areas were covered via the listserv postings. Significant topics covered in the past year included media coordination for various study findings; news releases from HHS, NIH, NEI, and various organizations that participate in the Network; HHS Weekly Reports, which cover a broad variety of public health issues; Healthy Vision Month; the Network's Annual Meeting; and other topics. Discussions with Network members showed that these materials were useful to members, although they could perhaps be consolidated into a periodic compilation email.

3. Organizations that participate in the Network sometimes share news releases through the listserv, but not often. In the past year, only a little more than 30 news releases were posted on the listserv by more than a dozen organizations outside of NEI. These news releases covered a variety of topics, but typically related to the release of a new study at a grantee institution, or a new report or statement issued by a third-party organization. Given the scope of the Network, it would seem that many news releases disseminated by Network members are not regularly provided to the listserv.

4. Most of the current conversation on the listserv is from NE1 to Network members, although the listserv could serve a professional "chat" function among Network participants. With few exceptions, the content of the listserv is provided by NE1 with little feedback offered by Network participants. While this one-sided communication may keep members informed of NE1 activities, it neither enhances networking relationships nor provides opportunities for professional insights to be shared by a cross-section of academic, professional and governmental experts. When members do participate in the conversation, the tone of the listserv is buoyed and several other members often chime in. One example is a series of listserv emails last fall regarding a storyline on NBC's top-rated "ER," where a character played by Bob Newhart experienced macular degeneration. In the course of a couple days, eight different Network members weighed in with thoughts about the storyline and shared information about their respective responses to the program.

5. The emails often have 'Subject' lines that are vague. Most of the subject lines of emails sent to the listserv follow a pattern of frequently used subject lines (e.g., HHS Weekly Report, Network Members Post News Release, NEI VISION Network Meeting, etc.). Others, however, allow the reader to gauge the information without clicking on the email – enabling him/her to determine if the email is of interest (e.g., CDC Launches New Online Journal, Senior Writer/Media Specialist for NEI, NIH Statement About Outside Consulting Agreements).

A Closer Look: Website Content

Questions considered when evaluating website content:

- Who maintains the Network website?
- How frequently is it updated?
- How does its visual appeal enhance/detract from its usage?
- Are monthly usage statistics available? What trends do they show? Was new information added in peak months?
- Does the website meet the needs of its audience?

Evaluation Findings

1. The Network website is clear and easy to navigate. The website lists clear headlines such as "Our Mission," "Member Institutions" and "News" with each headline linking to corresponding sections. The "Projects" section, however, did not contain any current or archived Network and member projects.

2. The 'Members Only' section contains concise, relevant information. This section provides members with access to the listserv, member contact information, job opportunities, news releases, projects and upcoming events. A FAQs section is useful for those not familiar with the inner workings of a listserv.

3. Communications to Network members involve the NEI website, but not the Network website. All 12 messages sent to the listserv reflected a posting or an update about the NEI website, but none referred to communications on the internal VISION Network website. Discussions with Network members showed that, although they periodically visit the Network site, they do not frequently contribute information or content to it.

4. Network members are kept regularly informed of improvements to the NEI website via the Network listserv. Of the 12 email messages regarding the NEI website, members received three email updates alerting them to updates on the NEI website over the course of 2003-2004. The first was issued in November 2003, followed by an update in December. The remaining messages were distributed at quarterly intervals: March, June and September 2004. Updates provided a substantive range of relevant topics for Network members, including website image catalog links, patient brochures and other development programs. Discussions with Network members showed that they find the NEI website updates helpful, but feel such updates might be even more useful if placed in a weekly or monthly compilation email.

A Closer Look: Annual Meeting Materials

Questions considered when evaluating Annual Meeting materials:

- What is the history of attendance at the annual meeting?
- What topics have been featured? Which topics have attracted the most interest? Do these topics relate to the Network's cited goals?
- If a participant attends one annual meeting, is he/she likely to return? Why or why not?

Evaluation Findings

1. Network members received frequent communications about the 2004 annual meeting. Information about the 2003 and 2004 annual meetings was readily available and easily accessible to Network members on the website. Listserv messages containing information about the 2004 meeting were sent frequently to Network members.

2. Network members were highly involved in planning meeting sessions and were offered opportunities at the meeting to share information about their organizations. Subject matter of annual meeting listserv communications was clear and detailed, and included meeting information and requests for Network input on a variety of matters, including a call for institution virtual tours and educational materials, suggested topics for roundtable discussions, and recruiting panel volunteers. Discussions with Network members revealed the value of involving members in meeting sessions and whether the occurrence of these requests was too frequent or not. No listserv messages were available for the 2003 meeting.

3. The 2003 and 2004 annual meeting programs were comprehensive and

informative, although the layout did not make finding basic information simple. While the printed annual meeting programs did contain valuable, pertinent information, the agenda was further back in the program. When evaluating meeting content, it would be easier for the user to have agenda items and meeting objectives closer to the front of the program book. Items such as the Network member listing and meeting planning committee could instead be further back in the program.

4. Attendance at the 2004 meeting was lower than that of the 2003 meeting. In 2003, the total number of meeting registrations represented 79 percent of total Network membership for that year (68 registrations). In 2004, the total number of meeting registrations represented only 60 percent of total Network membership for that year (54 registrations). While these percentages are extraordinarily high, there nevertheless was a 19 percent decline in one year. Interviews with Network participants, however, indicated a great deal of satisfaction with the meeting. If attendance continues to decline in 2005, a more comprehensive survey on the annual meeting should be conducted to determine the reasons behind the reduced registrations.

5. The 2003 and 2004 VISION Public Information Network annual meetings were clearly valuable to Network members. For both years, overall meeting evaluation scores were in the top tier of the rating scale. Of most value to Network members were those sessions most applicable to Network members' roles within their organizations. For example, attendees of the 2004 meeting gave rave reviews to *Crisis Communications: Having a Plan*, the professional development session and the roundtable discussions. In 2003, the media panel and professional development sessions earned top scores. Although most members found scientific sessions interesting, they did not earn the top scores that other sessions did. Network member are eager, however, to explore new terrain as topics to discuss at the Annual Meeting, such as marketing, fundraising, community relations, etc.

A Closer Look: Member Survey Reports

Questions considered when evaluating member survey reports:

- Has the Network previously polled or surveyed its membership?
- Do the surveys occur on a regular basis?
- What do the surveys reveal?

Evaluation Findings

1. The Network listserv is an ideal platform for surveying Network members, although response rates are varied. Several surveys and requests for feedback have been distributed via the Network listserv over the past two years. Response to these surveys has been mixed. While the member survey of department chairs, deans, and presidents to assess the value of the Network for member institutions received a 24 percent response rate (38 surveys returned), the timing of this survey may have prevented more members from responding. This survey was sent out to members on March 1, 2004, just one month prior to the annual meeting, and at the same time there were many other annual meeting emails coming from NEI to the listserv.

A second member survey regarding customer service complaints only garnered four responses. Although this survey was well-written and easy to respond to, it was unclear from the initial listserv message why this survey was being done and how the results would be used. This may have prevented more members from responding.

Discussions with Network members indicated whether the frequency of member surveys is too often or not. It also revealed the value of survey results to each member institution.

III. MEDIA AUDIT

Background

To determine how NEI messages and research results are reported by the media, GYMR evaluated a sampling of 250 media clips provided by NEI. The articles were published between October 2003 - October 2004. Media clips were qualitatively reviewed for tone of coverage, and both qualitatively and quantitatively reviewed for key message inclusion, type of publication and scope of coverage.

For this evaluation, NEI provided print clips from Burrelle's tracking service and video, and print and web clips collected by Ogilvy Public Relations. GYMR designed a set of evaluation codes to record: type of media outlet, type of article, reporter, topic, key messages, institutional mentions and spokespeople quoted. Each clip was evaluated using these codes; the results were recorded and evaluated.

Overarching Conclusions

1. NEI-generated media materials seem to directly affect the quality of coverage received by grantee institutions. The media frequently used key messages supplied by NEI to the Network members – 100 percent of the articles GYMR analyzed included information from the Network's message boxes.

2. The Network appears to increase the media's frequency of quoting both NEI and a local institution in reporting on a study result. Most reporters quoted more than one source in their stories, which often included NEI and a local grantee. In fact, 20 percent of coverage on the Los Angeles Latinos Eye Study (LALES) study included both, which demonstrates success in reaching two of the Network's objectives – highlighting the role of grantee institutions in conducting federally funded research and informing the public about NIH's mission to improve the health of America through medical research.

3. Roughly half of the Network members use and appreciate the media materials supplied by NEI. Those who do not, say that different departments in their organization generally handle media relations. Based on our interviews with Network members (see page 21), we believe that members are well aware of the media materials that NEI provides to them. About one-third said they use and appreciate the media materials, particularly the template news releases, for coordinating information on a study release. The materials for macular degeneration were frequently cited as being particularly useful and relevant. Another third said they use the news releases, but not for dissemination to the media. Instead, they use the news releases to inform their colleagues. A final third said they rarely or never use the media materials. These respondents said that their job generally does not encompass media relations. While some said that they forward these materials to other departments for possible use, they are not heavily utilized.

A Closer Look: Key Findings from Media Audit

The following are key findings from the media audit:

1. The majority of coverage appeared in consumer publications. Nearly all of the clips that were analyzed appeared in consumer print publications or on consumer websites. Only 11 clips appeared in trade publications.

• The release of the NEI National Plan for Eye and Vision Research received the most trade coverage, with five clips in various NewsRx publications.

2. Coverage of studies significantly increased because influential syndicated reporters reported on them. NEI studies received widespread consumer media attention. The Early Treatment for Retinopathy of Prematurity Study (ETROP), LALES and Prevalence of Blindness Data (PBD) were the top media stories. News syndicates drove the coverage of all three by placing an article written by a syndicated reporter in numerous outlets.

- Seventy-five percent of PBD clips resulted from a story written by Lindsey Tanner of the Associated Press.
- Forty-five percent of ETROP clips were syndicated from a separate story written by Lindsey Tanner.
- Thirty-eight percent of LALES clips resulted from a story written by Veronica Torrejon of Knight Ridder and 18 percent from a story written by Daffodil Altman of the LA Times, which was also distributed through the LA Times syndicate.

3. NEI messages were repeated by the news media. GYMR was provided message maps for ETROP, LALES and Ocular Hypertension Treatment Study African American Results (OHTS-AA).

- One hundred percent of the articles on these three studies included messages from the corresponding NEI message map.
- The most common messages were those pertaining to the general study results. NEIspecific messages such as, "The ETROP was conducted at 26 centers nationwide and funded by the National Eye Institute" were less commonly picked up by reporters.

4. NEI was often mentioned as study funder. Coverage of NEI studies often cited NEI or NIH as the study funder.

- Ninety-three percent of PBD clips, for example, mentioned NEI, the NEI website or NEI spokespeople.
- At the same time, 75 percent of PBD clips mentioned NIH, the NIH website or NIH spokespeople.

5. Overall, the tone of the coverage was positive.

- Reporters and media outlets responded positively to research results and presented positive stories.
- Stories created a favorable tone for NEI and NIH.

6. In general, most reporters quoted more than one source, which often included someone from NIH/NEI.

- Twenty percent of LALES study clips included a quote from an NEI or NIH spokesperson.
- NET Director Dr. Paul Sieving, was quoted in the NewsRx coverage of the National Plan for Eye and Vision Research.

IV. INTERVIEWS WITH NEI / NIH STAFF

Background

To gauge internal perceptions of the Network, GYMR interviewed eight professionals who are either NIH staff members or who are consultants who work closely with NEI. These interviews provided insights into internal perceptions about the value of the Network, its role in sharing information with grantees, its challenges and opportunities for the future and its relevance to the larger NIH community.

An interview script was developed with NEI staff, and interviews were conducted via telephone in 15-minute increments. Interviewees were chosen to represent a range of perspectives, including NEI staff and consultants who work on communications issues, leadership of the Institute and members of its research staff. The interviews were not taped, but detailed notes were taken. Complete confidentiality was assured.

Overarching Conclusions

1. The Network is perceived internally at NIH and NEI as being highly valuable in advancing NIH's mission by sharing communications in a systemic, timely way. Repeatedly, we heard that the work of the Network has solidified relationships with grantees and enhanced the quality of communications shared with each other and the general public regarding vision research. Staff members who do not manage communications recognize the benefits of the Network.

2. NEI staff believe the Network's potential to help grantees share information with each other is largely untapped. GYMR also heard this from Network members later in the evaluation process.

3. There is a large opportunity for NEI to present the Network as a model to other institutes within NIH. Individuals both inside NIH and at grantee institutions told us that other institutes need to be aware of the VISION Network model and how it helps coordinate and improve communications between grantees and NIH.

A Closer Look: Key Findings from Staff Interviews

1. The Network is perceived internally as a highly valuable resource. Virtually all interviewees lauded the Network as significantly helping to improve and increase communications between NEI and its grantee institutions and other vision-related organizations. It was also cited as helping to build relationships and provide professional development.

"The VISION Network has helped establish closer working relationships with grantees and enhance their relationships with NEI – particularly in terms of communicating research results to the public."

"It's not enough to just conduct the research. We also must communicate the results to the public, doctors and other researchers so they can take advantage of the information, and so the taxpayers can see where and how their money is being spent. The Network helps us do all that."

"I hear that for individuals, being a part of the Network can help them get recognized in their own departments. They have news to report and share because of the Network – it raises their profiles."

2. The Network is seen as advancing NIH's mission and benefiting grantee institutions by sharing communications materials and information in a systematic, timely fashion. All of the interviewees believe that the Network is responsible for helping to coordinate information among grantees and others, particularly in preparing vision-related research for public release. The Network is seen as providing coordinated, well-crafted communications that local institutions can use in their own media relations efforts.

"The Network helps manage the story that is going out to the public. It's important that different groups are on the same page, and the Network has been helpful in doing this. Connections and relationships are made through Network relationships and that helps too."

"The Network helps connect us to the extramural community so when we have research to announce, we can take messages directly to local communities and academic health centers. It's a great model."

3. People who do not work closely with the Network do not have strong familiarity with its actions or goals. While those who frequently work with the Network have a clear understanding of its accomplishments, other staff members – including those who work on communications issues or who work closely with NEI communications staff – do not always feel they have a clear understanding of what the Network is working on. Some interviewees seem to believe the Network is a "best-kept secret" among vision experts who work in communications. They feel that it could be shared more fully with others, including researchers and administrators, so that they can better understand the role of Network communications in their research endeavors.

"There is a community of people, myself included, who do not really know what the goals of the Network are."

"Often the deans and presidents and chairs of departments are not involved in the Network, so they don't hear about it. But if they become familiar with it, I think they appreciate it."

"Higher-level people just don't appreciate the extent to which these people work to get their research communicated. They don't know or appreciate what is being done. The clinical research folks might have a better understanding because it is discussed in regard to dissemination strategy, but they all could benefit from knowing more about the Network."

4. The Network's potential to help grantees share information with the larger vision community is perceived as largely untapped. Nearly all interviewees expressed disappointment that members do not use the Network to share their own information with each other, but instead only as a way for NEI to communicate with them. The interviewees said that they desire more of a dialogue with the Network participants versus one-way communications.

"Sometimes we're caught by surprise by Network members. We see a study in the newspaper that we didn't even know they were communicating. There is room for improvement."

"Almost all of the communications are from NEI, with a few coming from Network members. They should share and interact more with each other – that would be ideal."

5. Experts believe that the Network can and should be a model that other NIH institutes might wish to follow. Interviewees perceive the VISION Network as something unique that should be shared with others at NIH. Suggestions included presentations to the Council of Public Representatives, and to communications directors at CD meetings or the communications retreat, presenting to institute directors at a meeting, and presenting to research directors as a model for disseminating findings and involving local grantees.

"NEI can serve by example. I think the other ICs should learn more about the Network so they can assess for themselves the accomplishments of it and the way it is set up. The Network's goal is one that all ICs need to pay attention to – they aren't accomplishing it as well as NEI."

"NEI has done a great job of coordinating releases with local institutions and they should share how they have done that and get the other ICs talking about what they might do."

V. INTERVIEWS WITH NETWORK MEMBERS

Background

GYMR interviewed 22 professionals who are members of the Network in order to gauge external perceptions of the Network. These interviews provided insights into external perceptions about the value of the Network, including how its communications role benefits Network participants, as well as identifying challenges and opportunities for the future.

An interview script was developed with NEI staff, and interviews were conducted via telephone in 15-minute increments. Interviewees were chosen from the ophthalmologic and optometric fields, and represent a range of leadership expertise and membership status within the Network. The interviews were not taped, but detailed notes were taken. Complete confidentiality was assured.

Overarching Conclusions

1. Overwhelmingly, members see their involvement in the Network as a tool to help them do their job. Opportunities to interact with colleagues and stay abreast of current issues in vision research are viewed as essential components of job performance. Almost all of the Network members GYMR interviewed greatly value their NEI affiliation and want it to continue and evolve.

2. Many members do not directly work with the media and believe program and listserv content should address a broader range of issues. Several members said that while they manage communications, actual media relations were not part of their job portfolio. They believe the Network would be even more useful if it included discussions on topics such as organizational marketing, clinical trial recruitment, fundraising, etc. However, these members still found value in Network materials, saying the information helped them add value to their institutions and earn the respect of colleagues.

3. Members desire more interactive communication among Network participants. Interestingly – and similar to findings from the NEI staff interviews – members wish listserv messages and website functionality were more interactive, but admit that they rarely post information.

<u>A Closer Look: Key Findings from Network Member Interviews</u>

1. Network participants believe their involvement in the Network helps them perform their professional duties. Whatever their job function or background, nearly all interviewees cited the Network as a valuable resource that helps them do their jobs. Members singled out NEI staff (and contractors) and the high quality of services provided. A handful of members, however, said that Network activities are often not directly applicable to their daily tasks. On closer analysis, it is clear that Network members come from a variety of disciplines, and these disciplines shape their perceptions of the Network's offerings. Some view themselves as PR professionals who work on medical research and eye issues; others view themselves as medical research or eye experts who are assigned to coordinate communications tasks. Those who self-identify as PR staff view their role as more of a marketer, fund-raiser and meeting planner, rather than a media relations expert. Therefore, in its meetings, mailings and offerings, the Network must continually try to meet the needs of members who come from diverse backgrounds and have different interests.

"The Network keeps me very current and up to date with NIH. It gives me so much information that I can relay to my colleagues – it makes me more valuable to my organization."

"I came from a different background and was recruited to this job. Although I had some knowledge of what went on here, the Network has been very helpful with coordinating study announcements by crafting messages, giving insights and guiding me through it. It's all really helpful."

"The information that's sent to us, I really wouldn't be the one to actually send any of that information out. That's done through the university's public relations office, and so some I review and pass along to our doctors, and some I just read for my own edification. I enjoy seeing everyone at the annual meeting, though."

"I think NEI is incredibly progressive and that the rest of NIH should do what NEI has done. They really help researchers at the local level."

2. Members cite the annual meeting, the listserv and the website as the most valuable features of the Network. Network members consistently praised the annual meeting as the most valuable resource, offering substantial formal and informal networking opportunities. Messages sent via the listserv also rated highly as a useful tool, and many members utilize the website to determine information about other members, post jobs or review news releases.

"The annual meeting has been very helpful. Interconnection with other ophthalmology departments across the country has been useful, as well as receiving information that's allowed to be distributed via the listserv between departments and from NEI."

"The available information to the public in terms of b-roll and text to use for media is very helpful. I like it when I post a release and it's emailed to all members in the Network; it brings a level of credibility to the research. I think it's great, because I don't have to browse the Internet to find the release."

"I think the biggest feature is the annual conference. We don't have a huge ophthalmology department, so I serve as the only public information officer, and the annual meeting is a good opportunity to meet with other people who do this full-time."

3. The Network website and listserv communications are valuable features to members, but most members use these tools for receiving information, rather than communicating as a network. A majority of interviewees identified the website as one of the most valuable components of the Network. However, unlike other valuable features of the Network, the reason for its value was very specific to each member and differed greatly among interviewees. For example, some members only used the website to post their organization's news releases, while others only used it to access the membership directory. Others said they occasionally logged on to see what other organizations were doing, but never posted information from their own organization. Some use it only as a repository for NEI press releases. While these components are valuable functions of the website, it is interesting that almost all interviewees only used the website for one or two of its functions, and always in a static fashion, rather than as a portal for exchanging information with their colleagues.

In terms of listserv communications, virtually all interviewees appreciate the listserv communications from NEI. Getting the content and the frequency just right is a challenge, however, due to the vastly different interests of the members. Some, for example, love receiving information on public policy and legislative issues, while others say that this is meaningless to them. Some cite the information regarding NIH and DHHS as very useful for them and their colleagues, while others say that this information is distracting and they prefer to keep the Network for vision-specific content. One point of agreement seems to be that the volume of listserv communications is about right, but that frequency needs to be adjusted so it's not so "feast or famine." Members say they do not like more than one Network listserv message in a day, but that sometimes long spells pass with no information. They encouraged NEI staff to think about a consistent way to communicate with them and provide more "bundling" of similar topics so that if they are not interested, they simply don't have to read it.

"I go to the website only when there is an email alert about a press release and I can click straight through from the email. I won't visit proactively on my own."

"I go to the website and read all the listserv emails. I like them all. I like to see information from other institutions – it keeps us all on our toes to know what everyone else is doing and if we are doing it too – or doing something more than they are. Any messages with new information like new developments in research are valuable to me. And the FYI information on NIH and DHHS keeps us well rounded."

"The listservs are too frequent when two or three come in one day. If they could combine those, that would be better, because then there are times when there won't be any. But getting a bunch in one day is too much."

"I use the listserv text in articles I write on various diseases, and finding out what other network members are doing has helped. Last year we redid our website and I could seek information about other network members and see what they were doing with their websites."

"I've only logged on for follow-up if something comes through that I want to follow up on, but I don't have a lot of free time to browse the Network or read the listserv messages."

About half of the interviewees use and appreciate the media materials supplied by NEI. Those who do not say that different departments in their organization generally handle media relations. All members are well aware of the media materials that NEI provides to them, but responses broke down into three categories when asked about whether they are used.

About one-third of respondents said they use and appreciate the media materials, particularly the template news releases, for coordinating information on a study release. The materials for macular degeneration were frequently cited as being particularly useful and relevant.

Another third said they use the news releases, but not for dissemination to the media. Instead, they use the news releases to inform their colleagues.

A final third said they rarely or never use the media materials. They said that their job generally does not encompass media relations. While some of these respondents said that they forward these materials to other departments for possible use, they are not heavily utilized.

"I use the news releases regularly for our online newsletter. I always try to include NEI news materials for this newsletter."

"All of the media materials are useful to me. The b-roll and the formulaic information I use for diverse disease models and studies – the messages are useful. It's all very public-friendly. The materials are a nice marriage of simplicity and access to science. It makes it more compelling for the public to read."

"Usually our institution's PR department deals with that. I call them to make sure they've heard about anything new, but they're on the listserv and I don't usually have to tell them. I think they put some of it in the newsletters."

"We don't really use it. We have a media department that handles this, but I don't think they use any of those materials either."

5. Network participants view it as a unique coalition, unlike any others that most members belong to. Most members feel the Network is extremely unique in that it convenes experts who exclusively work on vision research. They also cited the fact that it combines both ophthalmology and optometry professionals. For some, this was a unique value of the Network. However, for others, this was perceived as a negative, and they cited the "competitive nature" and differing priorities of theses two professions. While many members belong to other professional organizations, most members could not identify other networks that they felt were similar to the Network, which they felt had specific benefits because it is a small, close-knit group that provides networking opportunities.

"There are other groups – the AAO, the AVO and others – that have their own newsletters and groups, but they're not in competition with the VISION Network. They're complementary."

"I see a major obstacle for the make-up of the Network, and I'm not sure how the Network will overcome it. The American Association of Ophthalmology just precluded optometry professionals from attending their national meeting. The VISION Network now includes both groups – but I would definitely prefer if they were separate. The marketing to these two groups is completely different. If our doctors are separating themselves, then maybe we should too."

"I can see why the Network combined ophthalmology and optometry; it makes sense. I don't know of any other organization that brings both together anymore."

6. Network participants value the Network and want it to continue, but would welcome a discussion about its future goals and possible future activities. A series of open-ended questions allowed Network members to discuss their expectations of the Network, its goals and ideas to consider in the future. Some toplines:

- There is confusion about the "goal" of the Network. Most members seem to view the goal as assisting with media placement, but meeting this goal is not a shared concern of all the Network participants.
- Job duties of Network members differ widely. Members view this as a strength that should be expanded and exploited by the Network rather than "just focusing on dissemination." Some view the diversity of the membership as potentially its greatest strength: some members can share insights on fundraising/development for their institutions; others can discuss media relations; others can provide best practices on coordinating research agendas across departments; still others can share best practices in marketing their institutions to researchers and the public. There is a strong sense that Network participants see their role as being a "jack-of-all-trades" rather than strict PR or media relations staff, and have expertise that they can share more widely with each other.
- Members learn from each other. The caliber of the Network participants (in terms of institutions represented) is clearly viewed as a strength. Members would like to see more case studies and hear "lessons learned" from each other.
- The Network should explore new projects. Network members are aware that it is their responsibility to make the listserv more dynamic and interactive -- which many seem to want -- and would welcome a discussion about how that could be possible. They also expressed a desire to pursue more public education projects together, such as the traveling eye exhibit.

VI. OUTSIDER INTERVIEWS

Background

GYMR interviewed a half-dozen health communications experts who are not members of the Network in order to generate ideas and gather insights concerning the effective communication of medical research to the public. These interviews provided insights into external perceptions about the value of medical communication networks and helped identify future opportunities for the Network.

An interview script was developed with NEI staff, and interviews were conducted via telephone in 15-minute increments. Interviewees were chosen based on recommendations from Network staff, and included vision and non-vision experts from a variety of institutions. The interviews were not taped, but detailed notes were taken. Complete confidentiality was assured.

Overarching Conclusions

1. The VISION Network is unique. Based on GYMR's analysis and interviews, there is no other network that functions in quite the same way as the VISION Network. Its imprimatur of NEI, in particular, gives it weight and importance that is not seen in other communications networks.

2. The "ideal communications network" would teach scientific experts about communications AND teach communications experts about the vision field. We repeatedly were told that the best networks for medical research personnel bring together the scientific / research experts with the communications experts to better understand each other's work.

<u>A Closer Look: Key Findings from Interviews with People Unfamiliar</u> with the Network

1. All unaffiliated vision experts interviewed felt that a major component to the success of a system such as the Network, which in part aims to disseminate information to the public, is ensuring that the information disseminated is timely and relevant, while remaining both scientific and comprehensible to its audience. Interviewees felt that the dissemination of relevant and factual information to the public and to network members is a key goal of this type of network. And while ensuring that the public receives factual, scientifically accurate material is important, people must also be able to understand and decipher the scientific information. Communications teams should make sure that the information disseminated is explicable to the public, and also have a working knowledge of the press and their issues of interest.

"The most important thing is that the information is factual, scientific, research-based and promotes the research within NIH and NEI."

"If it's a mechanism to provide communications to the members that assist in communications with their own constituencies, principally to the public, it has to provide timely, interesting materials that can be utilized by its members and the public."

2. Most interviewees were aware of other networks that existed within the vision community, but cited that no other was quite like the VISION Network. Interviewees were aware of several vision networks operating within organizations such as the American Academy of Ophthalmology, American Optometric Association and NEI's own National Eye Health Education Program (NEHIP), but no other network does quite what the Network tries to accomplish. Other observations note that the Network rises above other networks because it disseminates highly authoritative and objective materials.

"I'm aware of tons of them. There are networks through some grantee agencies that I can't quite recall the name of, but none of them are quite precisely what the VISION Network is trying to do, in terms of getting their information out to the public."

"I'm aware of several. But the most striking thing about NEI is that information comes with such authority and objectivity, and the validity of it is incomparable."

3. Communications personnel can improve their effectiveness by remaining knowledgeable about their subject matter and regularly interacting with other PR professionals. The interviewees unanimously felt that communications professionals should have a technical understanding of the vision field so that they can effectively disseminate materials concerning vision research to their audience in an appropriate fashion. Communications professionals should also have opportunities to network, as at the annual meeting.

"I think it would be helpful if they pull the PR people together at their annual meeting. It seems to help those organizations that come and share ideas . . . I think it's important that the PR folks have an opportunity to get together to brainstorm ideas."

"The principle is the same for any of these networks—you want to have a clear idea of what is timely and appropriate for your audience so there is some level of information for what their target audience is interested in. The individuals who put the information together must know fully what the subject is about, and all relevant stakeholders should have been queried and included in the process." 4. Vision experts provided several recommendations concerning Network activities that would be useful for the VISION community. Suggestions included offering an onsite NIH tutorial to members that would give them a more complete background about what the NEI contributes to vision research, hosting an awards ceremony to recognize members and potentially working with a charity to promote research. NEI's traveling eye exhibits were also praised as a useful resource, but it was suggested that NEI offer them in a wider range of locations.

"NEI has several traveling eye exhibits, and I think those are going well. Maybe their approach of placing them in malls is correct, but for those of us in rural areas without significant malls around, we get bypassed and people can't participate. It's also very expensive from a local level to sponsor, so maybe if they did these on a smaller level, it would be worth it."

"Perhaps a tutorial on NIH 101 is an option?... They should see if people want to come to NIH and get a feel for it. Maybe they could also look at the model of the National Association of Science Writers. At their recent meeting, they had very interestingly titled sessions that were about professional development as well as about learning how to work with specific agencies... Another thing that is important is to give awards. It's a way to recognize outstanding institutions for their contributions."

VII. REVIEW OF OTHER NETWORKS

Background

After interviewing numerous Network members, it became very clear that the VISION Network is a unique organization unlike any other that the members belong to, or are aware of in the vision community.

GYMR conducted a comprehensive online search, therefore, to identify comparable organizations and found the same thing to be true: to our knowledge; there is no other organization quite like the VISION Network.

There are, however, similar communications networks within and outside of the health community. As NEI recognized when it began its Network a decade ago, other organizations now realize the importance of offering their constituents a loosely structured network to share insights and ideas, enhance the professionalism and skills of the group, and – when the issue is a common one among the members – to share tools for communicating key messages to the public, other colleagues and media.

GYMR identified six organizations with offerings that are similar to those that the VISION Network provides to its members. While several of these networks do not directly relate to eye issues, they nevertheless are useful examples for illustrating what other networks – some from other industries – are doing to more effectively communicate their messages. Not all of the components will be applicable to the Network, but many may bring insight or spark ideas for concepts the Network could implement to enhance communication of eye health and clinical trial results.

A Closer Look: Key Findings from Review of Other Networks

American Academy of Ophthalmology (www.aao.org)

<u>Overview</u>

Although the American Academy of Ophthalmology (AAO) is a professional society and not a communications network, it does provide some interesting products that are useful to reporters and of which NEI should be aware. Of the many organizations that cater to eye professionals, this one seemed the most relevant for comparison to VISION Network activities.

Communications Tools

1. *Newsroom:* The AAO's newsroom provides breaking news and updates covering the entire field of ophthalmology and occasionally includes materials from sources other than AAO. This includes archived news releases and radio soundbites.

2. *Media Matters: Media Matters* is a quarterly newsletter for members and media produced by the AAO's communications group. Topics covered include AAO's media activities, useful and interesting soundbites, quick tips and recent news releases.

Example: The September issue of *Media Matters* included talking points and articles of interest for Cataract Awareness Month and Children's Eye Health and Safety Month, coverage of Academy media activities, useful sound bites, quick tips and recent news releases.

3. Specialty Information Teams: AAO Specialty Information Teams (SIT teams) provide regular news and information updates for AAO members in nine subspecialties on the AAO website. The SIT Team members are leaders in their field who contribute new and exciting information from domestic and international meetings, abstracts or journal articles.

Comment / Analysis

While the AAO does not have a formal network dedicated to communications, they do have several mechanisms in place to keep members who are interested in communications – and reporters – up-to-date on current issues in ophthalmology. The Newsroom could present an opportunity for housing NEI press releases. The SIT teams might be interested in learning more about the Network and how it is working across the field to coordinate communications. The *Media Matters* newsletter could feature an article on the uniqueness of the Network.

eyeOrbit (www.eyeorbit.org)+

<u>Overview</u>

Primarily serving members of the American Academy of Ophthalmology (AAO) and its many state affiliates, eyeOrbit is "the official network for ophthalmology, eye physicians and surgeons." It is entirely web-based and serves as a portal for near-constant conversation on vision and eye issues. The network exists entirely as a series of "blogs." Blogs are an interactive format for Internet dialogue between numerous parties (often anonymous) on countless topics. The blogs are supervised by a moderator and reach anyone who signs up to participate. Eye professionals, vision experts, students and others are encouraged to blog and participate in the daily conversations.

Communications Tools

1. Blogs: A recent review found 52 active blogs being conducted on a range of topics that fall into 16 categories. Sample subject matters include: Internet publishing of medical research, ophthalmology competencies, glaucoma and optometrists performing surgery. The number of blogs varies from day to day, and there is no limit to how many separate communications may exist in a particular blog. It is clear that the site attracts significant activity each day.

2. *Student Forum:* The site strongly encourages participation from ophthalmology students and contains a separate Student Network forum for student-focused conversations.

3. *Events:* A calendar tracks events of interest to the profession, such as AAO meetings and other related activities.

Comments / Analysis

This site is <u>the</u> nexus for online communications about eye issues, albeit largely from the perspective of ophthalmologists. Although the audience is closer to the practice of eye care than the Network caters to, the Network might wish to make sure all of NEI's press releases are posted on the site. If NEI wishes to increase online discussion among its Network participants, this site shows how it is done.

National Cancer Institute (http://cabig.nci.nih.gov)

<u>Overview</u>

Based on our research, the National Cancer Institute (NCI) is <u>not</u> operating a communications network, but has launched a network designed to help coordinate activities and share data among its grantees, which has a small communications function. The program is called caBIG (cancer Biomedical Informatics Grid). It is an open-source, open-access, voluntary network of more than 50 cancer centers and other cancer experts. The goal is to agree upon common data standards and needs, and share information with each other in the hope of accelerating progress.

Communications Tools

1. *Website:* Although caBIG has many different components, the cornerstone is its website. caBIG and its website aim to become "the world wide web of cancer research." The site is an extremely sophisticated, well-funded portal of existing research that allows researchers accessing caBIG to rapidly convert and analyze data from many different sources to aid their own research. The site also contains many communications materials, such as an information kit to help cancer centers share their activities and achievements with the media, the public, colleagues, sponsors, associates and others. There also are downloadable materials, including press releases and fact sheets.

Comment / Analysis

caBIG is clearly aimed predominantly at practicing researchers, rather than the staff who communicate the results of the research, but it looks like it has big plans to grow. Reviewing its website is worthwhile, and NEI may wish to brief NCI staff on how it assembled and operates its Network, for it may have implications for future plans for caBIG. It is the only "sharing network" we discovered, aside from the consumer liaison groups that many institute directors have, including NCI.

National Public Health Information Coalition (www.nphic.org)

<u>Overview</u>

The National Public Health Information Coalition (NPHIC) is an independent organization of professionals who communicate about public health issues. Very closely (though not exclusively) tied to the Centers for Disease Control and Prevention (CDC), NPHIC is a channel through which directors of public health information in America's states and territories may exchange and share communication methods, techniques and information to help improve technical skills and public health communications. It is very much a grassroots organization, involving people who work for not-for-profit organizations; local, state and federal agencies; and academic and/or medical research institutions.

Communications Tools

1. *Newsroom:* This password-protected website area is designed primarily for members and journalists as a resource of public health news, information, links and images.

2. **NPHIC News:** Rather than use a listserv, NPHIC communicates to its members through a newsletter, published every other month. Current and past copies can be reviewed on the website.

3. Annual Conference: The annual conference is clearly the major activity of the organization, and CDC plays a large part in shaping the agenda and sharing information. Programs can be reviewed on the website. The conference also features an awards program for "best campaign" and "best brochure."

4. Publications: NPHIC occasionally develops simple publications for its members, such as a "The Media and You," a pamphlet that provides tips for handling media interviews, with lessons learned about communicating on public health issues.

<u> Comment / Analysis</u>

Public health communications advocates are a notoriously disparate group. NPHIC was developed as a way to help public information officers share news and tactics to maximize their programs, much as the Network does. NPHIC's conferences, newsletter and publications may provide useful fodder and ideas for the Network.

National Network of Public Health Institutes (www.nnphi.org)

<u>Overview</u>

This is a young organization that links public health professionals who work for a Public Health Institute (PHI). A PHI is typically a statewide entity that receives funding from many stakeholders across a state to function as a convener among many local groups. The goal is to increase the flow of information among groups and improve skills. The organization operates with seed money from CDC and the Robert Wood Johnson Foundation. Much of its work is not focused on communications, but some of it is.

Communications Tools

1. *Calendar:* The website has a master calendar where all organizations post their events and meetings.

2. **Conference:** The annual conference is a highlight event. Much of the focus is on specific public health interventions, but there typically is a communications component – usually a case study regarding a successfully coordinated public health campaign.

3. *Newsletter:* The organization does not operate a listserv, but instead produces a monthly newsletter (online) for its members.

4. *Reports:* The website serves as a repository – with a search function – for reports and information released by all of the members.

5. *Forums:* There is a "chat room"-style function on the website, but it is closed to visitors and available to members only.

Comment / Analysis

While not directly similar to the composition of the Network, its basic structure is similar and the website is worth reviewing. The "reports" archive is particularly thorough, and a similar product might be useful for vision-related researchers and communications experts.

The Communications Network (www.comnetwork.org)

<u>Overview</u>

The Communications Network is a non-profit membership organization that provides the philanthropic community with leadership, guidance and resources to promote strategic communications in philanthropy. Its role is to raise awareness about the importance of communications and identify resources that will make not-for-profit organizations and foundations more effective.

Communications Tools

1. *Events:* The Network offers bi-monthly learning workshops via a conference call that provide professionals with the opportunity to network, share ideas and learn more about their respective practices.

2. *Grantee Communications Resource Center:* This is an online center that provides grantees with communications support, including media toolkits, peer networking, a monthly newsletter, workshops and a resource library.

3. *Listserv:* Information about the network is sent out to subscribers via a listserv on a monthly basis.

4. *Regional Programs:* Organizations conduct regional communications programs in their own communities.

5. *Conferences:* Two annual conferences are offered – providing members with opportunities to network and share information about effective practices within philanthropic organizations.

6. *News Section:* The news section provides network updates across the country.

<u>Comment / Analysis</u>

The structure of the Communications Network appears similar to the VISION Network in several ways. Like the VISION Network, the Communications Network offers a variety of resources to its participants, such as a listserv, networking opportunities and an annual conference. The Communications Network also appeals to communications officers, trustees and program staff. Its website is worth reviewing, and the "Regional Programs" section and "Grantee Communications Resource Center" may be of particular interest.

VIII. SUMMARY: EVALUATION CONCLUSIONS

1. NEI's VISION Network is unique and improves its members' professional

abilities. NEI staff, Network members and outside professionals all believe that there is no other Network quite like the VISION Public Information Network. Especially unique for its diverse membership and distribution of accurate, timely information, the Network helps its members become invaluable assets to their organizations by allowing them to keep up-to-date on current research and events within the vision field.

2. The Network's offerings are well-produced and well-utilized. Overwhelmingly, members of the Network praised the annual meeting, listserv and the website as the most valuable offerings of the Network. Regardless of their specialty or professional role, members used these tools to communicate with each other and gather information.

3. Media coverage of study results is well-coordinated and messages are consistent. Based on GYMR's materials review and what the agency heard during member interviews, coordination of clinical study results is impressive. The Network is able to provide members at grantee institutions with the ability to easily communicate clinical trial results, while highlighting both the role of the individual institution as well as the role of NIH / NEI. No small task, this is done extremely well via Network-generated materials and tools. This is also apparent from the coverage generated by Network activities. Articles were interesting, comprehensive and included key messages developed and communicated by the Network.

4. For many powerful audiences at NIH and the Network members' institutions, the Network is a "best-kept secret." GYMR spoke about the Network with high-level professionals within NIH and at leading academic institutions. Within the NIH – and at grantee sites – the Network was called "an example for other institutes." At the same time, officials both at NIH and at research institutions said that not enough people know what the Network does – even within their own organizations.

5. The Network's diverse membership has interests in communications beyond media relations. Brought together by the common goal of effectively communicating vision research to the public, members of the Network also share professional interests that extend beyond media relations. GYMR spoke to many members who are responsible for fundraising, internal public relations, marketing, community relations, and recruitment. Although the Network serves a valuable purpose for these members, there may be opportunities to expand Network activities to meet more of the diverse needs of its members.

Thoughts for the Future...

Although GYMR was given access to the workings of the Network, this evaluation has only scratched its surface. However, it is clear that there is a large opportunity to build on success. The Network's membership is a vibrant community of vision experts who, when tapped, seem willing to bring insight and ideas to the Network.

Based on what we heard, GYMR offers the following ideas to help set the stage for future discussions about possible plans for the future. The agency does not endorse any of these specific concepts, but believes they provide important food-for-thought for planning the next phase of the Network.

- Convene a discussion about the goal of the Network for the next 10 years.
- Launch one compiled listserv each month so important news and information is compressed into one email, instead of several different ones that may get overlooked.
- Hold scheduled blog or listserv discussions on featured topics to allow members to discuss other interests beyond media relations.
- Add a rotating "Featured Member" program on the website or an awards program for members to create a more interactive community.
- Consider Special Interest Groups (like marketing or fundraising) so members can share individual specialties with the Network.
- Conduct periodic NIH seminars such as "Communications 101" or "Vision 101" to meet the needs of the Network members and their colleagues who want to learn more about communications and / or vision research to better perform their duties.
- Discuss how / why of involving research / administration leaders from member organizations to participate in the Network.
- Discuss how to better entice members to share information with each other in an interactive way.
- Discuss how to share the Network's success with other NIH and industry entities.

APPENDIX

MEDIA AUDIT CONTENT CODES

<u>Outlet</u>

 (Open ended) – GYMR will enter the name, city and state of each outlet into the database

Type of Article

- Each clip will be coded as broadcast, print trade or print consumer
 - A1 broadcast
 - A2 print trade
 - A3 print consumer
 - o A4 Web

Reporter

 (Open ended) – when applicable, GYMR will enter the name of the reporter listed for the clip

Study Topic

- Each clip will be coded for mentions of the following studies
 - B1 Early Treatment for Retinopathy of Prematurity Study (ETROP)
 - o B2 Ocular Hypertension Treatment Study African American Results (OHTS-AA)
 - B3 Los Angeles Latinos Eye Study (LALES)
 - o B4 Prevalence of Blindness Data (PBD)
 - B5 Vision in Preschoolers Study (VIP)
 - B6 Eye Site Traveling Exhibit
 - o B7 Other

Key Messages

- GYMR will list NEI-supported messages that appear in the relevant clips. Codes will be developed for each study based on message boxes provided by NEI (currently, GYMR has message boxes for the ETROP, OHTS-AA and LALES studies)
 - D1 Includes message box messages
 - E1 message 1
 - E2 message 2
 - E3 message 3
 - E4 message 4
 - D2 Does not include message box messages
 - o D3 NA

Institutional Mentions

- Each clip will be coded for mentions of NEI, NIH and local institutions. When applicable, an article may be coded for multiple institutional mentions
 - o C1 NEI
 - C2 NIH
 - \circ C3 local institution
 - C4 HHS

Spokespeople Quoted

 (Open ended) – when applicable, GYMR will list the names of all spokespeople quoted in the clips

INTERVIEW QUESTIONS FOR NEI STAFF MEMBERS

Thank you for taking the time to speak with me about NEI's VISION Public Information Network (Network). My name is ______ and I work for GYMR Public Relations. We have been engaged by the NEI communications staff to evaluate its Network program, which was created by the National Eye Institute about 10 years ago for the purpose of communicating vision research results to the public.

This interview is only one part of our evaluation – over the next several months we will be working with NEI to evaluate Network materials and media clips and will conduct additional interviews with some of your colleagues, Network members and others. Once those elements are complete, we will provide NEI with an analysis of our findings.

Regardless of your familiarity and experience with the Network, your answers to these questions will give us insight into the Network from an internal point of view and will be very useful to us.

This interview is strictly confidential. We will not connect your name to specific answers for anyone. Your response will only be used in our evaluation and assessment of the Network.

<u>Questions</u>

- 1. Would you say your familiarity with the Network is very familiar, somewhat familiar, or not very familiar?
- 2. Does the Network enhance or advance the NIH's overall mission? If yes, how? If no, why not?
- 3. Does the Network benefit grantee institutions? If yes, how?
- 4. Do you hear feedback from grantee institutions, department chairs, deans or presidents of schools and colleges of optometry about the Network? If yes, what are some of the comments you've heard?
- 5. In your opinion, do you believe the Network has increased media coverage of NEIsupported research results?
- 6. Do you have greater access to or greater knowledge of what is happening at NEI's grantee institutions due to the Network's efforts?
- 7. What is your role in coordinating the release of vision research results? How often do you do this?
- 8. Can you explain to me how NEI staff either benefit, or could benefit, from the Network? Let's break "staff" down into 4 categories: (a) leadership (b) researchers (c) communications staff and (d) extramural staff.
- 9. Do you ever log on to the Network website? Attend the annual meeting?
- 10. Do you see new or different opportunities for the Network now and into the future?
- 11. What do you think may prevent the Network from always reaching its goals?
- 12. Do you think the Network could serve as a model for other ICs at NIH? If yes, tell me more about that how would it happen what could NEI do?

INTERVIEW QUESTIONS FOR VISION NETWORK MEMBERS

Thank you for taking the time to speak with me about NEI's VISION Public Information Network (Network). My name is ______ and I work for GYMR Public Relations. We have been engaged by the National Eye Institute communications staff to evaluate its Network program so they can continue to meet the needs of its members.

This survey is only one part of our evaluation – over the next several months we will be working with NEI to evaluate all facets of the Network, including communications materials, media results and NEI's coordination of the Network.

Your answers to these questions will give us insight into the Network from a member's point of view and will be very useful to us. This interview is strictly confidential. We will not connect your name to specific answers for anyone. Your response will only be used in our evaluation and assessment of the Network.

- 1. Has the VISION Public Information Network been of value to you in doing your job?
- 2. Which 2 or 3 Network features provide the most value to you?
- 3. Does your Dean, President, or Department Chair support your involvement with the Network?
- 4. Do you use the news releases and/or messages and b-roll disseminated by NEI? If yes, which materials are most useful to you and why?
- 5. Would you say the Network has helped you increase media coverage of NEI-supported research results for your institution?
- 6. Do you ever log on to the VISION Network website? If yes, what is the usual purpose for your visit?
- 7. Do you read most messages sent via the listserv? If yes, which messages are most useful to you?
- 8. Do you feel the frequency of listserv communications is just the right amount, not frequent enough, or too frequent?
- 9. Do you feel that you are well informed of Network activities?
- 10. Do you feel the Network keeps you well informed of news and information about NIH and DHHS?
- 11. Have you ever attended a Network annual meeting?a. If yes, when did you attend?b. If no, why haven't you attended?
- 12. If you've attended an annual meeting in the past, did you find the marketing information about the meeting to be too much, not enough, or just right?

- 13. If you've attended an annual meeting in the past, did you find the program content valuable?
- 14. How does the Network compare to other professional organizations that you belong to?
- 15. Do you use the Network to share any of the following items?
 - a. Press releases/media announcements
 - b. Job postings
 - c. Events
 - d. Projects
- 16. If you don't use it for these purposes, why not?
- 17. Do you pass along information from the Network to other members of your institution?a. If yes, to whom did you pass the information?b. If no, why not?
- 18. Do you always notify NEI when your institution will be reporting on NEI-funded research results? If no, why not?
- 19. Are you aware of any other networks similar to the VISION Public Information Network? If so, which ones?
- 20. Do you have interaction with Network colleagues outside of Network activities?
- 21. Do you hear feedback from others about the Network? If yes, what are some of the comments you've heard?
- 22. What do you think may prevent the Network from always reaching its goals?
- 23. Do you see new or different opportunities for the Network now and into the future?

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OUTSIDER INTERVIEWS – VISION EXPERT TELEPHONE SURVEY

Thank you for taking the time to speak with me about the VISION Public Information Network (Network). My name is ______ and I work for GYMR Public Relations. We have been engaged by the NIH's National Eye Institute to evaluate a public affairs Network the NEI coordinates with its grantee institutions. I know you are not affiliated with the Network, but you are an expert in vision issues and have familiarity with communications.

We understand that you are busy and are not soliciting your involvement in the Network.

In terms of background, NIH's National Eye Institute has coordinated the VISION Public Information Network for 10 years. The Network links public affairs professionals – mostly affiliated with academic institutions – who communicate about vision research for information-sharing and professional development.

I'd like to ask you a few questions about effective communications regarding vision research. Your insights will be valuable to us.

This interview is strictly confidential. We will not connect your name to specific answers for anyone. Your response will only be used in our evaluation.

- 1. Have you ever heard of the Network? If yes, what are some of the comments you've heard?
- 2. In your opinion, what would make this type of Network valuable for participants? (Probe for response: media activities; increase knowledge of vision issues; skills building; networking, etc.)
- 3. Are you aware of other formal or informal networks that exist in the vision community? (Probe for information and ideas.)
- 4. Have you ever participated in a research announcement that involved numerous organizations or institutions coordinating the media relations? Was it successful? (Probe: why or why not....)
- 5. Communicating about medical research that pertains to vision health takes special skills. In your opinion, how could communications personnel who work on these issues improve their effectiveness? (Probe)
- 6. Are there any types of activities that you believe the Network could undertake that you think would be useful for the VISION community?

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OUTSIDER INTERVIEWS – NON-VISION EXPERT TELEPHONE SURVEY

Thank you for taking the time to speak with me about the VISION Public Information Network (Network). My name is _____ and I work for GYMR Public Relations. We have been engaged by the NIH's National Eye Institute to evaluate a public affairs Network the NEI coordinates with its grantee institutions. I know you are not affiliated with the Network, but you are an expert in communications.

We understand that you are busy and are not soliciting your involvement in the Network.

In terms of background, NIH's National Eye Institute has coordinated the VISION Public Information Network for 10 years. The Network links public affairs professionals – mostly affiliated with academic institutions – who communicate about vision research for information-sharing and professional development.

I'd like to ask you a few questions about effective communications regarding medical research. Your insights will be valuable to us.

This interview is strictly confidential. We will not connect your name to specific answers for anyone. Your response will only be used in our evaluation.

- 1. Have you ever heard of the Network? If yes, what are some of the comments you've heard?
- 2. In your opinion, what would make this type of Network one that links communications experts from various institutions who all work on similar issues valuable for its participants? (Probe for response: media activities; increase knowledge of vision issues; skills building; networking, etc.)
- 3. Are you aware of other formal or informal networks similar to this that exist? Are you part of any? What do they do? (Probe for information and ideas.)
- 4. Have you ever participated in a research announcement that involved numerous organizations or institutions coordinating the media relations? How did it work? Was it successful? (Probe: why or why not....)
- 5. Communicating about medical research takes special skills. In your opinion, how could communications personnel who work in medical research improve their effectiveness? (Probe)
- 6. Are there any types of activities that you believe a Network like this could undertake that you think would be useful for its members?

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Patrick McCabe GYMR Public Relations 1825 Connecticut Ave., NW Suite 300 Washington, DC 20009 Phone: 202-745-5100 Fax: 202-234-6159 E-mail: pmccabe@gymr.com Web Site: www.gymr.com