THE OPHTHALMOLOGIST OUTREACH PROGRAM FOR THE LIONS LOW VISION REHABLITATION NETWORK (LOVRNET)

Background

The success or failure of Lions LOVRNET, or any other strategy for providing low vision rehabilitation services, depends to a large extent on the knowledge, attitude and practices of ophthalmologists with respect to low vision rehabilitation. Although ophthalmologists are exposed to low vision rehabilitation services as part of their residency training, based on participation in the American Academy of Ophthalmology's Vision Rehabilitation Special Interest Group (AAO Vision Rehabilitation SIG), fewer than 0.5% are directly engaged in providing these services to their patients. But, the worse situation is that most ophthalmologists do not refer their visually impaired patients for low vision rehabilitation. Because most people with low vision currently are, or recently have been, an ophthalmology patient, the ophthalmologist is the de facto gate keeper to low vision rehabilitation services.

Several reasons have been offered in the ophthalmology literature for why so many ophthalmologists do not refer their patients for low vision rehabilitation, but perhaps the simplest explanation is that the ophthalmologist, who primarily is trained as a surgeon, can directly observe the structures of the eye, in many cases down to the cellular level using advanced technology. They also can accurately and precisely measure the optical quality of the eye and can measure visual impairments with a high degree of accuracy, precision and sophistication. Because so much useful and important information about eye pathology can be obtained from direct observations and measurements, heavy emphasis is placed on the structure and function of parts of the eye with the principal aim of diagnosing and treating the patient's ocular disorder. In most cases, very little history information is needed from the patient to make the diagnosis and plan treatment. In short, most ophthalmologists, especially those treating the eye diseases that are responsible for most low vision, spend very little time talking to their patients and, because of their overloaded patient schedules, do not ask the kinds of questions that might lead to lengthy and emotional narratives about the consequences of the patients' visual impairments on their daily lives.

Although many of the ocular disorders can be controlled and future damage slowed or limited, the leading causes of low vision cannot be cured with currently available treatments. Unfortunately, many patients are not treated until some amount of irreversible damage has been done to their vision – indeed, reduced functional capability from lost vision is often what motivates the patient to seek help from the ophthalmologist in the first place. Although the functional consequences of visual impairment may have motivated the patient to see the ophthalmologist, the patient's complaints are not the focus of the ophthalmologist's attention and much too frequently are ignored, or deferred and forgotten. As a result, many patients with low vision are left to cope with their functional limitations on their own, often unaware of even the existence of low vision rehabilitation services.

Many ophthalmologists have inaccurate conceptions about the relationship between visual impairments and functional disabilities, especially in the older population. Many have had limited exposure to the details of modern low vision rehabilitation services that conform to the medical rehabilitation model.

Many are not aware of the evidence proving that low vision rehabilitation can be highly effective in restoring the patient's daily functioning and independence. And many ophthalmologists are concerned they could lose their chronic eye disease patients if they refer them to another eye doctor for low vision rehabilitation services. With respect to the latter point, most low vision services in the healthcare system are provided by optometrists, and the patient populations for ophthalmology and optometry heavily overlap. Although many optometrists and ophthalmologists have good working relations, there have been numerous instances of acrimony between the professions and since 2004 the American Academy of Ophthalmology has banned optometrists from attending ophthalmology educational meetings under its auspices. This official position of the AAO on optometrists undoubtedly reflects negative attitudes of its members toward the profession that is most often associated with low vision rehabilitation in the healthcare system.

Changing the knowledge, attitudes and practices (KAP) of ophthalmologists with respect to low vision rehabilitation is the goal of the ophthalmologist outreach program for the Lions LOVRNET. The transtheoretical model for stages of change is a popular framework for explaining the stages a person goes through during an educational program designed to effect a change in health behavior, e.g. smoking cessation programs, but the model applies to changes in any kind of behavior. The stages of change are described as 1) precontemplative (not intending to take action because the person is unaware of the problem, uninformed, misinformed, or had a negative experience that drove them into denial), 2) contemplative (learning about the problem and developing an intention to change), 3) preparation (serious intention to take action, acquiring knowledge and resources needed to overcome barriers and act), 4) action (implementation of the behavior change and evaluation of the consequences), and 5) maintenance (reinforcing the behavior change and making the changed behavior routine and sustainable) (<u>http://www.uri.edu/research/cprc/TTM/detailedoverview.htm</u>).

Recognizing a problem, in 2003 the AAO Vision Rehabilitation SIG tried to change ophthalmologists' KAP toward low vision with the SmartSight program, a stepwise approach to managing patients who have low vision (http://www.aao.org/publications/eyenet/200501/low_vision.cfm). The SmartSight program primarily focuses on instructing ophthalmologists how to educate their low vision patients about available services and resources for the visually impaired and refer any patients who have visual acuity less than 20/40 for low vision rehabilitation (level 1), or alternatively provide some level of low vision rehabilitation services within their own practice following AAO Vision Rehabilitation Preferred Practice Pattern[®] Guidelines (levels 2-4). Although there has been no formal evaluation of the impact of the SmartSight program, anecdotally there appears to have been an increase in awareness about low vision rehabilitation since SmartSight was implemented, but otherwise it appears to have had little effect on ophthalmologists' practices over the past decade. In part, the apparent lack of impact of the SmartSight program may be because SmartSight is long on advice about the right thing to do for low vision patients, but short on practical solutions for overcoming the barriers to acting on that advice. In terms of the transtheoretical model for stages of change, SmartSight may have moved many ophthalmologists from the precontemplative stage to the contemplative stage, but it stopped there and much more needs to be done to eventually reach the action stage. Because the Lions LOVRNET will create a "no excuses" environment for ophthalmologists to follow the SmartSight recommendations of their own professional

society, the ophthalmologist outreach program for the Lions LOVRNET will be built on the foundation of the AAO SmartSight Program and the AAO Vision Rehabilitation Preferred Practice Pattern Guidelines.

Approach to Developing and Evaluating the Lions LOVRNET Ophthalmologist Outreach Program

The ophthalmologist outreach program has 5 aims:

- Determine the states of knowledge about low vision and low vision rehabilitation, attitudes toward low vision rehabilitation services and service providers, and their relation to low vision patient referral and service provision practices of the ophthalmologists in Maryland, Delaware, and District of Columbia (the Lions LOVRNET project area).
- 2. Develop ophthalmologist outreach program content and materials and assemble resources (e.g., ophthalmologist role models, brochures, online videos and presentations) needed for Lions to implement the program.
- 3. Match ophthalmologists with Lions Clubs in their catchment area and train Lions and provide them with resources, model programs and access to professionals to educate ophthalmologists in their community on the AAO SmartSight program, the AAO Vision Rehabilitation Preferred Practice Pattern Guidelines, and Lions LOVRNET resources available to them and their patients.
- 4. Implement a campaign with the local Lions Clubs to enroll their assigned ophthalmologists in the Lions LOVRNET, provide them with patient education materials, provide LOVRNET training programs for their staffs, provide volunteer transportation services to doctor appointments for their patients, and engaging their ophthalmologists in local public eye-health education and vision screening programs that include an emphasis on low vision rehabilitation.
- 5. Evaluate outcomes and the impact of the Lions LOVRNET Ophthalmologist Outreach Program.

To create an incentive for ophthalmologists to participate, the Lions LOVRNET ophthalmologist outreach program will be implemented using the Lions Eye Health Program (LEHP) and the MD22 Lions Public Education Program on Low Vision and Blindness as vehicles. These two programs have strong and worthy missions in their own right that complement the Lions LOVRNET mission. The LEHP objectives are:

- **Encourage the early detection and timely treatment** of diabetic eye disease, glaucoma and agerelated macular degeneration (AMD), and the appropriate treatment for low vision.
- Help educate people at risk for eye disease and encourage them to seek appropriate treatment.
- **Establish community activities** that promote awareness of eye health. These include distribution of eye health materials at appropriate locations (doctors' offices, senior citizens centers, schools, youth groups, health fairs and other venues), vision screenings and eye health presentations.
- Increase awareness of the network of eye health organizations concerned with diabetic eye disease, glaucoma, AMD and low vision. Local collaboration with these organizations may provide useful resources for Lions interested in promoting awareness of eye health and the causes of preventable vision loss.

The objectives of the Lions Public Education Program on Low Vision and Blindness are:

- Combat stereotypes and social stigma associated with low vision and blindness by educating the public on the capabilities of blind and visually impaired people so that the public better understands how blind and visually impaired people can lead normal, productive, and rewarding lives.
- **Teach the public how to interact with blind and visually impaired people**, respect their rights, eliminate discrimination, and offer and provide assistance without embarrassment or insult.
- **Teach the public about the value and effectiveness of low vision rehabilitation** and about the programs and resources available to blind and visually impaired people in the community.

Education materials and resources for LEHP are available from Lions Clubs International and the National Eye Institute/ National Eye Health Education Program. Education materials and resources for the Lions Public Education Program on Low Vision and Blindness are available from the Mutliple District 22 Lions Vision Research Foundation. The LEHP program in particular is important to community ophthalmologists because it educates and screens members of the community for preventable and treatable eye diseases such as cataract, glaucoma, diabetic eye disease, age-related macular degeneration, and other causes of low vision and encourages people who are identified to be at risk to see an ophthalmologist for examination and treatment. It is important for community ophthalmologists to work closely with local Lions Club members to plan and execute LEHP screening and education programs for their area. The incentive for ophthalmologists to participate is that both LEHP and the Lions Public Education Program on Low Vision and Blindness create opportunities for ophthalmologists to market their practices to people in the community and to guide programs that will increase their patient volume.

The aims the Lions LOVRNET ophthalmologist outreach program will be accomplished in the following ways:

Aim 1. Evaluate KAP for low vision rehabilitation among area ophthalmologists. A sample of area ophthalmologists who routinely refer patients for low vision rehabilitation services and a sample of area ophthalmologists who do not will be recruited by local Lions in different Districts to participate in regional workshops to plan local eye health and vision screening programs for elderly community dwellers (i.e., LEHP). During the workshops, participating ophthalmologists will be interviewed using a standardized survey to elicit their recommendations about how to screen and follow-up for diabetic eye disease, glaucoma, age-related macular degeneration, and low vision. They will be asked to comment on published recommendations in these three areas including the AAO SmartSight program, the AAO Vision Rehabilitation Preferred Practice Pattern Guidelines, and LEHP and NEHEP public education material. They will be asked to give their advice on the role of ophthalmologists, optometrists, occupational therapists, vision teachers, rehabilitation counselors, and social workers in providing low vision rehabilitation (LVR) services; the relationship between visual impairment measures and patients' functional abilities; the traits of patients who need each type and level of LVR service; the quality and effectiveness of available LVR services; and their own low vision patient management practices. The interviews will be recorded and transcribed recordings will be coded and analyzed by Johns Hopkins researchers.

Aim 2. Develop education program content and resources. Based on the results of Aim 1, the project team will develop the content and assemble the resources for the ophthalmologist education program.

Content will cover topics such as summaries of published papers on the relationship of functional ability to visual impairments and how these relationships are modified by other aspects of low vision patients' physical and mental health; the results of epidemiological studies forecasting the explosive growth of low vision over the next two decades; the results of clinical research on patient outcomes of LVR services; the details of the AAO SmartSight program and the AAO Vision Rehabilitation Preferred Practice Pattern Guidelines; the details of the medical rehabilitation model for LVR and Medicare coverage of LVR; details of Lions LOVRNET operations, services, data collection, outcome measures, reporting, quality control, and continuous provider education; reports on new low vision assistive technology and procedures (e.g., implantable miniature telescope); case reports and patient testimonials; reports on opportunities to participate in collaborative studies (e.g., benefits of cataract surgery for patients with low vision); and continuing medical education courses on providing LVR services. Education resources will include: online video vignettes and presentations on selected topics; white papers that can be downloaded; webinar case conferences; invited speakers at regional CME courses; patient education materials; JCAHPO-accredited clinic staff training programs; and online dashboards for analyzing patient outcome data (integrated with the Lions LOVRNET system).

Aim 3. Match ophthalmologists with local Lions Clubs and train Lions Club members. Each practicing ophthalmologist within the LOVRNET project area will be matched with a Lions Club in their patient catchment area. The Lions Clubs, in cooperation with their District leadership, will participate in Region or Zone LEHP planning meetings in consultation with their assigned ophthalmologists. They also will invite their assigned ophthalmologists to make presentations at Lions-hosted public education events on blindness and low vision. Region-level workshops and online training programs will be developed and offered to Lions to train them how to work with the ophthalmologists.

Aim 4. Implement campaign for Lions Clubs to enroll local ophthalmologists in LOVRNET. A Multiple District 22 (Lions LOVRNET project area) campaign will be launched with each Club given goals to enroll their local ophthalmologists in LOVRNET and to provide them with LOVRNET education resources and volunteer services to their patients. The Wilmer project team and LOVRNET administration will provide guidance and assistance with recruitment to the Clubs.

Aim 5. Evaluate education program outcomes and impact on LVR service delivery. Patient referrals to LOVRNET by project area ophthalmologists, whether care is being transferred to another doctor or the ophthalmology practice is providing LVR services themselves using LOVRNET resources, will be tracked by the LOVRNET system over time to provide data that are required to evaluate changes in ophthalmologists' practices. The LOVRNET system also will schedule and track volunteer services provided to patients by Lions Club members and LOVRNET-sponsored educational activities of each Club. LOVRNET's online learning management system also will track activities of ophthalmologists who view video vignettes, presentations, and take CME courses.

Coordinated Program Plan

The Lions LOVRNET Steering Committee will organize Lions at the Multiple District 22 level to operate the Lions Eye Health Program, offer training programs to Lions, and coordinate its activities with the

Lions LOVRNET ophthalmologist outreach program. The Lions LOVRNET Steering Committee will appoint a Lion to be the LEHP/ outreach program coordinator for MD22 (to be approved by the LVRF Board). Each of the 5 Districts will be asked to create a LEHP Committee representing each Region in the District and appoint a chair, if they do not already have one.

The Lions LOVRNET administrative office will match each ophthalmologist who practices in each District to local Clubs, Zones, and/or Regions. The District LEHP Committees will be provided contact information for the ophthalmologists matched in their District. On behalf of the respective Regional LEHP Committee members, the Lions LOVRNET administrative office will send a short survey (with coded stamped pre-addressed reply card) to each ophthalmologist in MD22 that describes the LEHP program, lists the Clubs that will be serving their catchment area, along with Club contact information, and asks: 1) if they will accept referrals of diabetic eye disease, glaucoma, AMD, and other potential eye patients screened by LEHP and, if so, allow their practice information to be included in local LEHP public education materials; 2) be willing to advise the LEHP Committee during the development and planning of community education and screening programs; 3) be willing to make presentations and answer questions at community eye health education programs; and 4) be willing to display in their patient waiting areas free LEHP patient education materials on low vision rehabilitation. The results of the survey will be tabulated and distributed to the District LEHP Committees.

The traditional low vision rehabilitation component of LEHP will be augmented with the MD22 Lions Public Education Program on Low Vision and Blindness and with Lions LOVRNET online and printed education materials for both the public and physicians, which will include information about the AAO SmartSight program and the AAO Vision Rehabilitation Preferred Practice Guidelines. The Lions LOVRNET will produce and offer JCAHPO-certified online courses for ophthalmic technicians that teach them about modern low vision rehabilitation services and how the services are covered by third-party payers; how to refract low vision patients; how to identify patients who require low vision rehabilitation services; about the low vision care coordination and quality control services of the Lions LOVRNET; and how their practice can refer visually impaired patients to Lions LOVRNET to be matched with appropriate and qualified local low vision rehabilitation service providers.

A devoted section of the MD22 lionsvision.org website will be constructed to provide information and announcements on LEHP programs in each District to both the public and to doctors. Model screening and education programs and materials will be assembled by the District LEHP Committees coordinated and led by the MD22 LEHP/Lions LOVRNET outreach program Coordinator with the advice and assistance of Wilmer faculty (particularly for Aims 1 and 2). The goal of this coordinated effort is to conduct annual LEHP vision screening and public education programs throughout MD22 and to keep practicing ophthalmologists engaged and contributing to the program. Not only will this program serve the intended public eye health need, but it incidentally will create and sustain a channel for educating ophthalmologists about the importance and benefits of low vision rehabilitation for their patients and the scope and availability of Lions LOVRNET services. In this way, Lions LOVRNET resources can be used to advance the objectives of LEHP, and LEHP activities will advance the objectives of Lions LOVRNET.