

## *Diabetic Retinopathy Position Paper*

SightFirst Long Range Planning (SFLRP) Working Group  
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### *Introduction*

The mission of the Lions' SightFirst program is to support the development of comprehensive eye care systems to fight the major causes of blindness and vision loss and care for the blind and visually impaired. The program funds high quality, sustainable projects that deliver eye care services, develop infrastructure, train personnel and/or provide rehabilitation & education in underserved communities.

Diabetic retinopathy, a complication of diabetes that occurs as a result of vascular changes in the retina, accounts for nearly five percent of the world's 37 million blind. Fortunately, vision loss from the disease can be prevented with good control of diabetes and timely diabetic retinopathy treatment. Since 1995, SightFirst has provided US\$2.5 million to support diabetic retinopathy screening and treatment projects in eight different countries. With funds from Campaign SightFirst II, Lions can expand these efforts to meet the growing eye care needs of people with diabetes.

This paper, prepared as part of a long range planning effort mandated by the SightFirst Advisory Committee (SAC), recommends strategies to guide future SightFirst diabetic retinopathy programming.

### *Diabetic Retinopathy*

#### *Disease Profile<sup>123</sup>*

Diabetes occurs when the body is unable to produce or properly use insulin, the hormone responsible for converting food into energy for daily life. There are currently 246 million people with diabetes worldwide and it is estimated that this number will rise to 380 million by 2025, with the largest increase taking place in developing countries. Type II diabetes accounts for the majority of cases and is largely preventable with a healthy diet and regular exercise. Nearly 4 million deaths each year are attributed to diabetes and long term complications include cardiovascular disease, stroke, kidney disease and amputations.

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<sup>1</sup> International Diabetes Federations (IDF), [www.idf.org](http://www.idf.org); Facts & Figures, Did You Know, Prevalence.

<sup>2</sup> World Health Organization (WHO), [www.who.int](http://www.who.int); Priority Eye Diseases.

<sup>3</sup> U.S. National Eye Institute (NEI), [www.nei.nih.gov](http://www.nei.nih.gov); Facts About Diabetic Retinopathy.

Diabetic retinopathy, another complication of diabetes, is the result of changes to the blood vessels of the retina, the light sensitive tissue at the back of the eye. In some cases, the blood vessels swell and leak, while in others, there is abnormal growth of new vessels. The disease usually affects both eyes and most often occurs in individuals having diabetes for many years. Diabetic retinopathy is the leading cause of vision loss in adults of working age (20-65) in industrialized countries.

Once vision is lost from diabetic retinopathy, it cannot be restored. Fortunately, progression of the disease and loss of vision can be reduced by 90 percent with improved control of diabetes and ongoing diabetic retinopathy treatment. Treatment options include laser surgery to help shrink vessels or, in more serious cases, vitrectomy surgery to remove blood from the center of the eye. Rehabilitation and regular eye exams are critical to maximizing treatment benefits.

Finally, given the chronic nature of diabetes, treatment for any complication, including diabetic retinopathy, is long-term in nature and most impactful when provided as part of a patients' overall diabetes care.

#### *Model of Care*

From a public health perspective, there are three levels of care related to diabetic retinopathy. The primary level focuses on the prevention of diabetes itself through *health education activities* targeting high-risk populations. These activities can be carried out by volunteers in conjunction with local diabetes associations and medical providers.

The secondary level of care is prevention of the progression of diabetic retinopathy for those diagnosed with diabetes. This can be done effectively through community-based *screening & treatment programs*. These programs require 1) a team of trained individuals to screen and refer patients; 2) ophthalmologists trained to diagnose diabetic retinopathy and perform laser treatment, and; 3) adequate equipment and facilities to provide these services. In addition, volunteers are often needed to help organize screening events, transport patients to and from regular treatment sessions and aid with payment for services.

Finally, at the tertiary level, there is provision of retinal *surgery* and *low vision rehabilitation* for those with extensive diabetic retinopathy and visual impairment. These activities require 1) specialized ophthalmologists to perform surgery; 2) trained low vision personnel, and; 3) adequate equipment and facilities to provide these services.

#### *SightFirst & Diabetic Retinopathy*

Since 1995, SightFirst has approved US\$2.5 million for 17 diabetic retinopathy projects in: India (4), Brazil (4), Pakistan (3), Fiji (2), Bahrain, Chile, Spain & Venezuela. The projects have been comprehensive in nature with activities ranging from public education and professional training, to screening, treatment and low vision services.

A formal evaluation of four of the projects was conducted in 2004 by World Health Organization (WHO) experts, SightFirst technical advisors and LCIF Sight Programs Department staff. Findings indicated the following elements of success:

- Community-based patient awareness campaigns in partnership with national or state organizations concerned with diabetes
- Community-based diabetic retinopathy screening programs, in collaboration with established diabetes or eye care clinics
- Availability of eye care infrastructure with professionals trained in diabetic retinopathy detection, diagnosis and treatment
- Provision of basic equipment and treatment facilities as add-ons to an established clinic
- A good monitoring system for patient outcomes, tracking & follow-up
- Linkages to tertiary care centers with fully developed vitreo-retinal department to provide technical assistance and treatment

### *SFLRP Working Group Recommendations*

In April 2008, the SFLRP Working Group convened a meeting with Dr. R. Pararajasegaram, IAPB Affiliate & SAC Member, and Dr. Jill Keeffe, Professor, Centre for Eye Research Australia & SightFirst Technical Advisor, to review global diabetic retinopathy statistics, informally analyze SightFirst diabetic retinopathy projects to date and recommend strategies for future related efforts. Also present were PIP Clement Kusiak, Ed McManus and Phoebe Sebring, consultants for the SFLRP effort, and the LCIF Sight Programs Department staff. With this information and the findings of the 2004 evaluation, the SFLRP Working Group has developed the following conclusions and recommended strategies for future SightFirst support of diabetic retinopathy:

#### *Conclusions:*

- SightFirst should continue to support the development or expansion of diabetic retinopathy screening and treatment programs at well-established diabetes and eye care clinics. The strategies outlined in the section below provide a framework for future project development.
- The prevention of diabetes and related complications is of increasing interest to governments and other non-government organizations (NGOs). The Lions, through their SightFirst diabetic retinopathy programming, can play a lead role in advocating for improved diabetes and eye care.

- The close link between diabetes and diabetic retinopathy may result in new and advantageous partnerships between Lions and members of the medical community, NGOs and corporate donors.

*Strategies:*

### **1. Identify appropriate project sites**

*How?*

- ü Projects should be conducted only where diabetic retinopathy is a significant cause of blindness *and* where appropriate diabetes case management exists.
- ü Priority should be given to projects seeking to strengthen *existing* programs with a good track record; that is, those looking to add equipment, improve facilities and provide personnel training for successful diabetes and/or eye care clinics. The SAC may wish to consider start-up programs on a case-by-case basis for facilities with well-established eye care services.
- ü Projects should target people with diabetes who are unable to access diabetic retinopathy care because of economic, social or geographic barriers.
- ü Diabetic retinopathy screening & treatment projects should only be considered when such efforts do not detract from existing eye care services.

### **2. Help integrate eye care into comprehensive diabetes care**

*How?*

- ü Projects should target those already diagnosed with diabetes; they should not include general population diabetes screening activities.
- ü Only projects where diabetic retinopathy care is provided as part of or in close collaboration with patients' diabetes care providers should be considered.
- ü Project objectives should align with national and/or state diabetes prevention and treatment plans, where they exist.

### **3. Provide high-quality eye care services**

*How?*

- ü Projects must include a strong evaluative component with outcome measures.
- ü Projects must include patient monitoring & tracking systems.

- ü Projects must have linkages to tertiary eye care centers with vitreo-retinal expertise to provide treatment for referrals and technical assistance.
- ü Projects must have linkages to low vision care services.

#### **4. Create sustainable diabetic retinopathy services**

*How?*

- ü Projects should include significant cost sharing; in addition to SightFirst funding, support might also include public/private partnerships and in-kind donations of human resources, consumables and facilities.

#### **5. Engage Lions as volunteers & advocates**

*How?*

- ü Priority should be given to projects where there is significant opportunity for Lions involvement including the organization of health education and screening events with local eye care professionals and assistance with patient transportation.
- ü Priority should be given to projects where Lions plan to advocate for improved government support of diabetes and diabetic retinopathy prevention and treatment.

#### ***Next Steps***

Should the SAC approve the strategies outlined above, the SFLRP Working Group recommends the following next steps with regards to implementation:

- The SightFirst grant application, including funding criteria and guidelines, should be revised to better solicit projects that meet the new strategies.
- LCIF SightFirst staff should be provided with resources to train regional technical advisors and inform local Lions about the new strategies and grant application process.
- In addition, Lions leadership, LCIF SightFirst staff, and regional technical advisors might be empowered to advocate for projects that readily meet the new strategies, especially in countries where diabetic retinopathy services are of top priority.