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# Age-related oculopathies "in a nutshell" (patient education materials)

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#### Age-related oculopathies "in a nutshell" (patient education materials)

#### Abstract

Effective doctor-to-patient communication is an essential component of health care which is difficult due to the complicated nature of ocular anomalies. Glaucoma and age-related macular degeneration (AMD) are two very common causes of decreased vision among adults older than 55 years. This thesis outlines the steps in composition and printing of patient-education brochures which can be used to supplement the practitioner's description of the diseases. The brochures contain concise, descriptive statements combined with simple illustrations and are printed with large easy-to-read print, in both English and Spanish. They explain the nature, pathogenesis, treatment, and prognosis of Glaucoma and AM D.

Degree Type Thesis

**Degree Name** Master of Science in Vision Science

Committee Chair Nira Levine

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#### AGE-RELATED OCULOPATHIES "IN A NUTSHELL"

#### (PATIENT EDUCATION MATERIALS)

By

#### JAY WALLACE WALKER, BA

A thesis submitted to the faculty of the College of Optometry Pacific University Forest Grove, Oregon for the degree of Doctor of Optometry May, 1992

> FACULTY ADVISOR: NIRA LEVINE, EdD

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### **Biographical Information**

J. Wallace Walker grew up in Soda Springs, Idaho and attended Brigham Young University in Provo, Utah where he graduated with a BA degree in Spanish and a minor in the natural sciences. He later attended Pacific University College of Optometry in Forest Grove, Oregon where he was involved in the "Amigos" student volunteer group serving Hispanic communities at home and abroad. As a member of the Amigos organization he helped organize participated in eye-care missions to Baja Sur Mexico and Cuenca Ecuador as well as projects in the Portland metro area. He is a graduate of the Lighthouse externship in low vision in New York, New York, is a member of Beta Sigma Kappa optometric honors fraternity, Who's Who among students, and a recipient of the Forest Grove Lion's Club Scholarship. He plans to practice primary care optometry in association with ophthalmology with special interest in contact lenses, low vision and bi-lingual eye care.

#### Abstract

Effective doctor-to-patient communication is an essential component of health care which is difficult due to the complicated nature of ocular anomalies. Glaucoma and age-related macular degeneration (AMD) are two very common causes of decreased vision among adults older than 55 years. This thesis outlines the steps in composition and printing of patient-education brochures which can be used to supplement the practitioner's description of the diseases. The brochures contain concise, descriptive statements combined with simple illustrations and are printed with large easy-to-read print, in both English and Spanish. They explain the nature, pathogenesis, treatment, and prognosis of Glaucoma and AMD.

#### Introduction

We live in an information oriented society. Decisions about health care are often based on available information -- good and bad. A misinformed society may be unaware of treatment options or seek inappropriate treatment. This results in unnecessary cost and jeopardizes health and welfare. In addition, failure of the practitioner to effectively communicate often lessens the effectiveness of prescribed therapy and may ultimately result in litigation. There is a need for materials which practitioners can use to supplement their communication efforts and at the same time increase public awareness.

#### Statement of the Problem

The parameters of our profession are rapidly expanding, especially in the direction of ocular disease detection and care. As the mean age of our population increases, optometrists will surely be involved in the care of Age-related Macular Degeneration, and Glaucoma as well as other age-related ocular problems. Effective professional care will involve doctor-to-patient communication and education. In addition, our profession will benefit from enhanced public awareness of our abilities and expertise in these areas.

#### Project Objective

The purpose of this project was to create informational brochures, written in both English and Spanish, that a eye doctors can use to supplement their explain of the nature of an ocular problem and the rationale for the treatment plan. The practitioner can use the diagrams in the brochure to illustrate the problem, and then give the brochure to the patient as an at-home reference for review of any details that may have been forgotten or unclear. The patient's family members and friends can also refer to the brochure. In addition to being a *communications aid*, the brochure can serve as a *public relations aid*. The practitioner can easily stamp the name, address and telephone number of the practice on the cover.

#### <u>Methods</u>

This project involved several steps:

#### Step 1: selecting a subject

As a student intern at Pacific University I saw many patients who had early signs of age-related macular degeneration (AMD). During an externship at the New York Lighthouse low vision clinic I worked with many patients who had severe vision loss from the disease. I also had similar exposure to glaucoma patients. These relatively common ocular diseases were largely a mystery to the patients who had them and to their families. However, clinical evidence shows that the prognosis of these diseases is significantly improved if the patient *understands* the disease and *complies* with the prescribed therapy. Therefore, to me the choice of these two topics for my project was obvious and interesting. **Step 2: researching the subjects** 

All of the information and statements in the brochures can be referenced to recently published articles from ophthalmological journals and the Journal of the American Optometric Association. I gathered literature on the specific topics with help from Pacific University Library Services using *Medline* database and the *LION* database from Southern College of Optometry in Memphis, Tenn. I scanned the abstracts of recent articles for relevance to my project. I used the *Index Medicus* at Pacific University in the same fashion. I then located the respective articles, photocopied them and reviewed each one individually for pertinent information.

#### Step 3: writing the text

The organization of the brochures can be broken down into 5 basic categories:

1. Introduction (why is the topic important).

2. The nature of the disease.

3. Contributing factors, and risk factors of the disease.

4. Treatment and prognosis of the disease (including the patient's role).

5. Illustrations to supplement the text.

I condensed the information from the literature into basic informational statements under the above headings. Then I composed a text attempting to reflect the information in the most clear, concise and readable manner. This part was probably the most time consuming requiring literally hundreds of hours and resulting in over 20 drafts. Early on I made some crude sketches to help illustrate the text. I submitted the earliest drafts of the project to doctors and professors of optometry for comment on accuracy of content, and to one of my former English professors for critique of clarity and style. After further modification I

submitted drafts to non-professional and non-academic people for general critique and comment. During this process I was aided by suggestions from my Pacific U. faculty thesis advisor.

#### Step 4: art work and design

The layout of the brochures is *three-fold 8X10*" with a total of 6 columns. I did the type setting using *MS Word 4.0* software on a Macintosh computer. Another individual (see Acknowledgements), who has professional experience in graphic arts, composed the art work using my original sketches as a starting point, and provided valuable additional suggestions and ideas.

#### Step 5: obtaining the copyright

One can obtain a copyright for printed materials by filling out a form provided by the Federal Department of Copyright and Liscensure and returning it along with \$25 and a copy of the material. It will subsequently appear on the list of copyrighted materials available at the U.S. Government Bookstore.

#### Step 6: printing of the brochures

1. Layout of text and art work to press specifications which include appropriate margins, spacing and format.

2. A photographic negative is made of the art (text and diagrams).

3. The photographic negatives are then taped down to sheets of mylar.

4. Color tones for the art are screened to appropriate

"percentages" determined by spacing of dot reproductions. In this project we used two colors: reflex blue and p.m.s. red.

5. Each color tone is shot to a seperate sheet of film.

6. The photographic negatives are then "built" together and sent to the printer.

7. The printer converts the negative images back to positive images which are hung on the press cylinders containing ink wells. Ink adheres to the positive image and is printed to the paper. The paper for this project is dull white 70lb. product lithe.

8. After the appropriate drying time the printed brochures are sent to the bindery where they are trimmed to size and folded.

# THE PUZZLE OF GLAUCOMA

Glaucoma is a very common, yet very serious ocular disease. More than one million people in the U.S. are visually impaired from the disease, and over 67,000 are legally blind! Glaucoma occurs in many forms, but the most common form, called *primary open-angle glaucoma* (POAG), happens so slowly and so painlessly that a person may be completely unaware of it until significant damage has occurred.

Glaucoma is like a puzzle. Researchers have yet to fully assemble the puzzle, but they have found some of its pieces.

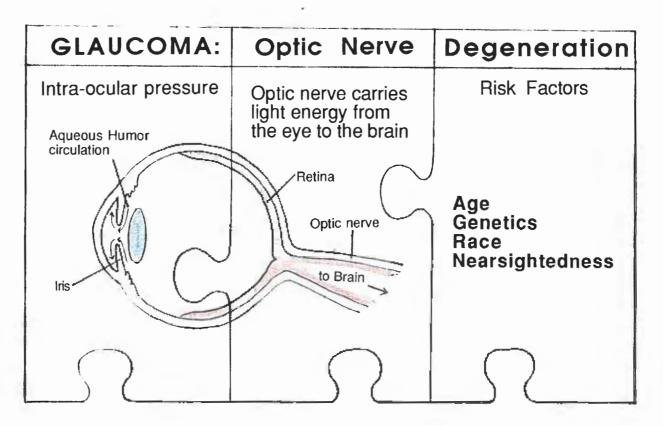
#### PUZZLE PIECE #1: The Optic Nerve

When you look at an object, its image falls on your *retina* (see diagram). Your retina sends signals via the *optic nerve* to your brain where they become "vision."

Glaucoma is a condition in which the optic nerve begins to degenerate. If left untreated it will result in blindness.

### PUZZLE PIECE #2: Intra-Ocular Pressure

Important structures in your eye are nourished by a special fluid called *aqueous humor* (see diagram). High levels of *intra-ocular pressure* (IOP), which you usually cannot feel, may cause damage to the optic nerve. This results in a characteristic reduction of the *field of vision*, which begins in the peripheral or "side" vision.



Aqueous humor continually circulates into and out of your eye. The circulation must be carefully regulated. If more fluid flows in and less flows out, the pressure inside your eye goes up.

At first the vision loss is unnoticeable, but it slowly advances until it becomes very severe. ADDITIONAL FACTORS

(puzzle piece #3,4,5,.....?) So far we know that glaucoma is a disease of the optic nerve and that it is associated with IOP. However, some people may have high IOP and not have glaucoma while others may have "normal" IOP and yet have the disease.

Factors in addition to IOP which may place a person at risk are:

**1. Age**. The older you are, the more likely you are to develop glaucoma.

 Genetics. Glaucoma tends to run in the family.
 Race. African-Americans are eight times more likely to develop glaucoma than people of other races.

4. Near-sightedness. How and why these factors contribute to the disease is unknown, and more puzzle pieces have yet to be found.

### TREATMENT OF GLAUCOMA

Currently there is no cure for glaucoma, but the disease can be managed to prevent vision loss. Treatment is aimed at lowering the intra-ocular pressure. Medication in the form of eye drops is commonly used to regulate the circulation of fluid. To be effective, the eye-drop method requires that the patient follow a strict schedule. *Failure to use the medication consistently and at proper time intervals is the leading cause of glaucoma blindness!* 

Remember, <u>glaucoma</u> (POAG) causes no pain! A patient will feel no improvement after taking the medication which is costly. and can be inconvenient. Complying with the therapy may be tough, but the alternative -- blindness -- is even tougher!

Advanced cases of glaucoma and cases that don't respond to medication often require specific surgical procedures.

### PUTTING THE PIECES TOGETHER

Your eye-care professional cannot make a diagnosis of glaucoma based on the presence of one or two of the puzzle pieces alone. Your doctor must carefully consider the characteristics of each individual. IOP, appearance of the optic nerve, visual field, age, race, and family history must all be considered together in order to begin to "assemble" the puzzle of glaucoma.

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## THE PUZZLE OF GLAUCOMA

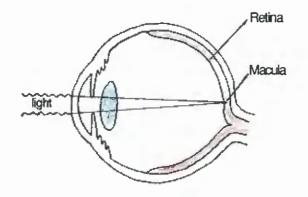


# "My vision just isn't what it used to be."

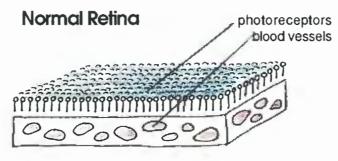
Reduced eyesight is one of the biggest health concerns associated with aging. The most common cause of reduced evesight, which cannot be corrected with regular eyeglasses, is known as age-related macular degeneration (AMD). AMD is the leading cause of irreversible vision loss among elderly people in North America. It occurs in about one in ten people ages 65-74, and in about *three* in ten people over age 75. It is a serious problem, and so far researchers have found neither its cause nor its cure.

### What is the macula?

The *macula* is the tiny area of your retina (see diagram below) which is most responsive to light -- the area that provides your "most distinct vision."

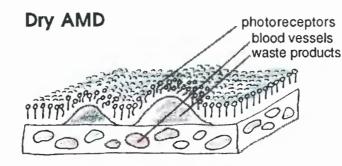


When you look at an object, the image of the object falls in the middle of the macula. The macula contains a high concentration of specialized cells called *photoreceptors* (see below). Photoreceptors convert light into nerve impulses which travel to your brain to become "vision."

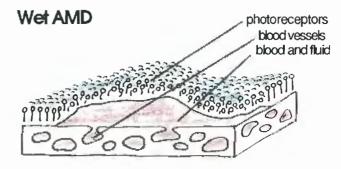


## How does AMD happen?

AMD is a condition in which the tiny photoreceptors in the macula degenerate (see diagram below).



*In the "dry" form* of AMD, waste accumulates beneath the photoreceptors and blocks the transfer of important nutrients from the blood stream. This results in a *gradual loss of vision*. *In the "wet" form* of AMD, blood vessels beneath the accumulation of waste begin to leak causing the formation of a pool of blood, fluid, and subsequent scar tissue. This can be devastating to vision!



#### Symptoms of "wet" AMD are:

] sudden, rapid vision loss ] reduced color vision

visual distortion

### Who will get AMD?

Many factors place an individual at risk. As the name implies, *age* is the biggest risk. The older you get, the more likely you are to get some form of AMD.

#### Other risk factors include:

- family history of AMD
- ] cardiovascular disease
- high blood pressure
- excessive exposure to sunlight
- ] light eye color
- ] poor diet
- cigarette smoking

### What if you get AMD?

Currently there is no treatment for the "dry" form of AMD. If it should progress to become "wet" AMD, expertly administered laser therapy can "coagulate" leaky blood vessels and *slow down* the visual loss. Certain microsurgical techniques may also help prevent severe vision loss. However, in order to be effective, these types of intervention must be done quickly, within hours or days!

## What can be done to avoid AMD?

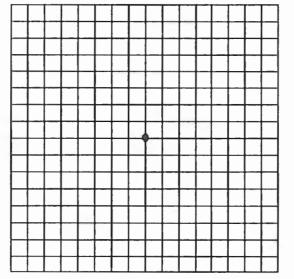
Many doctors suggest a few things to help preserve your vision:

- ] Sunglasses
- A well balanced diet
- Vitamin supplements
- that include vitamin C,
- vitamin A, and Zinc
- Yearly eye exams

# The most important thing that you can do:

- Frequent check-ups with
- your eye doctor  $\square$  Be aware of the
- symptoms of "wet" AMD
- Home monitor with Amsler grid

Home monitoring using an Amsler grid (see below) will enable you to detect any loss or distortion of central vision. If changes occur you must notify your eye doctor immediately! Wasted time is wasted sight!



AMSLER GRID

Hold the grid 12" from your face. Cover one eye and stare at the center dot (be sure to wear your reading glasses if you have them). Repeat the procedure with your other eye. If the lines appear distorted or broken, have your eyes examined right away.

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## AGE-RELATED MACULAR DEGENERATION



# La Rompecabezas de la Glaucoma

La glaucoma es una enfermedad que es muy común y muy grave. Más que un millón de personas in los EEUU tienen daño de la vista por causa de la glaucoma, y imás de 67,000 son ciegas! La forma más común de la glaucoma sucede gradualmente y sin dolor. Una persona no estará conciénte de ello hasta que haya resultado en mucho daño.

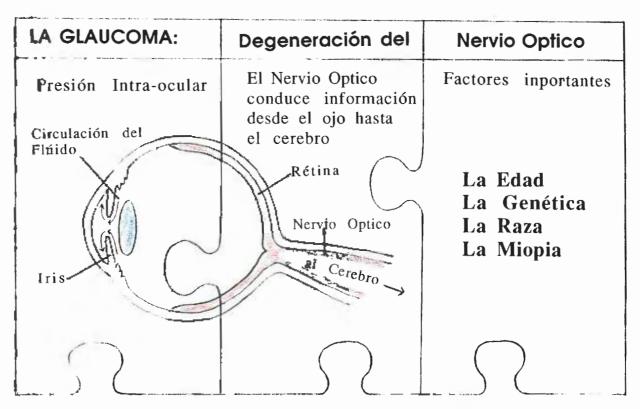
La glaucoma es como una rompecabezas. Los investigadores todavía no han resolvado la rompecabeza, pero sí, han encontrado algunos de los pedazos.

#### Pedazo #1: El Nervio Optico

Cuando Ud. mira a un objeto, la imagen del objeto llega a la rétina (véase la diagrama). La rétina manda señales por *el nervio óptico* hasta el cerebro donde se transforman en "la vista." La glaucoma es una condición en que el nervio óptico se descompone, y, si no se da tratamiento, resulta en la ceguera.

## Pedazo #2:

La Presión Intra-Ocular Estructuras inportantes del ojo reciben alimento por un fluido especial dentro del ojo (véase la diagrama). Niveles altos de *la presión intra-ocular* (PIO), lo cual no se puede sentir, pueden resultar en mucho daño al nervio óptico. El daño causa en la pérdida de la vista periférica, o sea, "la vista del lado."



Este fluido entra y sale del ojo constantemente. La entrada y salida se tiene que regular con mucho cuidado. Si más fluido entre al ojo de lo que salga, la presión adentro del ojo se subirá. Al principio no se nota la pérdida de vista,pero luego va progresando hasta que sea muy grave.

## Factores de más (pedazos #3,4,5.....?)

Hasta aquí sabemos que la glaucoma es una enfermedad del nervio óptico y que se relaciona con la PIO. Sin embargo, *muchas personas tienen la PIO alta sin tener la glaucoma, mientras que otras pueden tener la PIO normal y tener la glaucoma aún.* 

Factores además de la PIO que contribuyen a la glaucoma:

$\Box$	La Edad
$\overline{\Box}$	La Genética
$\Box$	La Raza
$\square$	La Miopia

Todavía no se sabe exactamente la manera en que estos factores se dan a la enfermedad, y aún más pedazos se han de encontrar.

## Tratamiento de la Glaucoma

Hoy en día no hay remedio para la glaucoma, sin embargo la enfermedad se puede controlar para que no haya pérdida de la vista. La meta del tratamiento es la de rebajar la presión intra-ocular. Medicamento en forma de gotas para los ojos se recieta para controlar la circulación del fluido. El éxito del tratamiento exije que el paciente siga un horario de instalación muy estricto. El fracaso de no usar el medicamento como corresponde es la causa mayor del la ceguera por la glaucoma.

Acuérdese: ¡la glaucoma (GPAA) <u>no causa dolor</u>! El paciente no ha de sentir ninguna diferencia después de usar el medicamento, que es muy caro y puede ser incómodo. El cumplir con el tratamiento es difícil, pero el alternativo -- la ceguera -- ¡es más difícil aún!

De vez en cuando hay casos de la glaucoma que no responden a la medicina. Estos requiren tipos espicíficos de la cirugía.

### Juntando los Pedazos

Su doctor de los ojos no puede hacer el diagnóstico de la glaucoma a base de la presencia de sólo uno o dos de los pedazos. Su doctor tiene que considerar los característicos de cada paciente. La PIO, la aparencia del nervio óptico, la vista periférica, la edad, la raza, y las genéticas se tiene que tomar en cuento para que pueda solucionar la rombecabezas de la glaucoma. ©1992 J. W. Walker, OD: Author /Designer printed in USA Carolee Romney: Illustrator Robert C. Gruter: Production

## LA ROMPECABEZAS DE LA GLAUCOMA

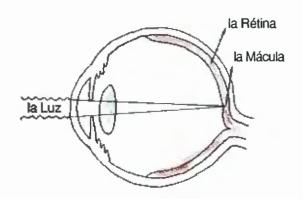


## "La vista mía no es lo que era."

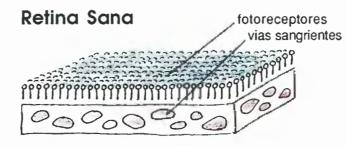
La reducción de la vista ocurre con mucha frequencia al llegerse a la edad más avanzada. De las causas que no se puede corregir con lentes regulares, la más común es una que se llama la degeneración macular de la senilidad (DMS). La DMS es la causa mayor de la pérdida de la vista entre aquellos con mayor edad en Norte America. Ocurre en 10% de personas de edad 65-74 y en 30% de personas que tienen más que 75 años. La DMS es un problema bien grave, y hasta ahora los investigadores han encontrado ni la causa ni la remedia.

### ¿Que es la mácula?

La *mácula* es la zona pequeña de la *rétina* (véase la diagrama abajo) que es la más sensible a la luz.

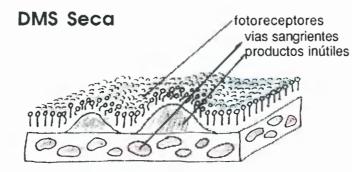


Cuando Ud. mira a un objeto, la imágen del objeto calle en el centro de la mácula. La mácula contiene muchas celdas especiales que se llaman los *fotoreceptores*. Los fotoreceptores cambian la luz a "la vista."

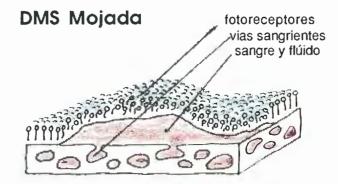


### ¿Qué pasa en la DMS?

La DMS es una condición en que los fotoreceptores de la mácula se degradan (véase la diagrama abajo).



*En la forma "seca"* de la DMS, productos inútiles se juntan abajo de los fotoreceptores e impeden la transladación de alimentos importantes desde la corriente sanguínea, el cual resulta en la pérdida de la vista gradual. *En la forma "mojada"* de la DMS, vias sangrientes debajo de los productos inútiles dejan escapar la sangre y fluido, y luego se forma la cicatriz. Lo resulta do es extremadamente dañoso a la vista.



#### Los síntomas de la DMS "mojada" son:

Ia pérdida rápida de la vista

] la reducción del sentido

del color

Ia distorsión de la vista

## ¿A quién le pasará la DMS?

Hay muchos factores que se dan a la DMS. Como implica el nombre, *la edad avanzada* es el factor mayor. Otros factores incluyen:

- historia familiar de la DMS
  infermedad cardiovascular
  - ] la presión alta
- 🔄 la luz del sol
- ojos claros
- la malnutrición
- fumar el tobaco

## ¿Y si a Ud. le resulta la DMS?

Hoy en día no hay tratamiento para la forma "seca" de la DMS. Si se cambia a la forma "mojada", terapía del láser se puede administrar *para impedir el progreso* de la pérdida de la vista. Sin embargo, para que sea eficaz ¡se lo necesita hacer dentro de pocas horas o días!

## ¿Qué se puede hacer para evitar la DMS?

Muchos doctores sugieren ciertas maneras de conservar la vista sana:

- 🗌 gafas para el sol
- 🗌 la dieta sana
- vitaminas que incluyen la vitamina C, la vitamina A, y el cinc.
- exámines anuales de los ojos

# Lo más importante que Ud. puede hacer:

- c exámines frecuentes con su doctor
- sea conciente de los
- síntomas de la DMS "mojada"
- 🗌 vigilar con una *reja de* 
  - Amsler

Vigilandose contra los cambios de la vista con una reja de Amsler (véase abajo) es la mejor manera de notar los cambios en la vista. Si algunos cambios se ocurren ¡avísele a su doctor inmediatamente! ¡El tiempo perdido es igual que la vista peredida!

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#### AMSLER GRID

Coloque la reja 30cm frente a su cara. Cúbrase un ojo y mantenga la vista fijada en el punto del centro (no se olvide colocar sus gafas de leer si los tenga). Repítalo con el otro ojo. Si las líneas se parecen quebradas o torcidas, obténgase un examen de los ojos lo antes posible.

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## LA DEGENERACION MACULAR DE LA SENILIDAD

#### <u>Conclusion</u>

These brochures will be a valuable asset and tool to use for management of patients with glaucoma and AMD. They are readable and appealing because of their colorful diagrams, large print and concise sentences. The Spanish versions will be valuable for anyone practicing in a bi-lingual area, such as the Pacific University Washington County clinics.

#### Future Projects

I intend to use what I have learned while doing this project to create additional patient information resources in the future. Future topics will include (but are not limited to):

-cataracts			
-contact lenses			
-the eyes and reading			
-multifocal lenses			

-vision and child development

-vision and safety

-optometry vs. ophthalmology

-diabetes and vision

Other projects will include short informational articles with diagrams to be used as advertisements in newspapers.

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Robert Gruter	Printing and layout
Amy Grotelueschen	General critique
Sue C. Walker	General critique
Eduardo Ugarte	General critique

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