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Low Vision and Uveitis

2008



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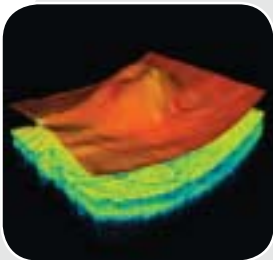
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The last 20 to 30 years have brought tremendous changes for uveitis patients. Today a lot of types of uveitis are better diagnosed, therefore bringing more efficient therapy. Drugs have clearly improved the prognosis not only for various types of uveitis, but also for complications like cataract, macular edema and glaucoma. In addition, progress in surgery also allows a better outcome. But even when in recent years the prognosis for many uveitis patients has become more and more favourable, there are still patients who develop severe forms of uveitis hardly responding to any therapy. They may lose visual acuity over the years significantly enough to suffer from reduced vision, especially when it comes to reading. This is called “**Low Vision**”, the major topic of the journal you have in your hands. Parallel to the improvement of the prognosis, fortunately a powerful “armour” of viewing aids has been developed, which can be seen for example in well equipped uveitis and ophthalmology centres.

This journal will inform uveitis patients about many different aspects of the low vision. Besides examples of vision aids we also give ideas about solving problems of daily living. Of course, low vision makes it more difficult to create art, music or to do sports, but all of these activities are possible, as we will show in these pages. patients should have the ambition and courage to use all these methods to suit their own needs.

We hope that we could create an interesting brochure for you again.

Manfred Zierhut,

President of the German Patient Interest Group,
Professor of Ophthalmology, University Eye Clinic of Tübingen,
Germany

August 2008



This journal has a mission that is most worthy. Many individuals must deal with uveitis and it is appropriate that they are put in touch with the resources that may be helpful to them. This publication will be valuable to both patients and to care providers who are interested in minimizing the impact of vision loss on life.

Health Care addresses itself to promote 'health', that is, as the World Health Organization (WHO) defines it, a condition of optimal physical, mental and social wellbeing. Acute medical care focuses on minimizing the impact of a disease on an organ system. But in spite of the best and most timely medical interventions, chronic conditions such as uveitis persist with permanent impairments that affect the quality-of-life of the individual, far beyond the organ system involved. Dealing with these issues is an integral part of medicine; it entails a different focus from that of acute care and is of course **Rehabilitation Medicine**. **Rehabilitation Medicine** touches almost all medical specialties. Its main goal, irrespective of the organ system or disease process involved, is to reduce the functional impact of various impairments, so that independence, productive activity and life satisfaction can be maintained. This goal is as appropriate for the visually impaired as any other type of impairment.

Ophthalmology has made great advances in the realms of acute medical care but has unfortunately lagged behind other medical specialties in rehabilitation medicine. With far too great frequency, those with vision loss are not being directed to rehabilitation professionals that can be of assistance. These patients often end up on the scrap heap of human life when there is great potential for a high quality and productive lifestyle. The tragedy of vision loss is not that people lose vision, but rather that they are not put in touch with the potentials that remain.

Vision loss has many different perspectives. A photographer walking around a piece of sculpture may get different impressions from

different points of view. A single snapshot, representing one single aspect, will not do justice to the entire work of art. Likewise, the condition of vision loss may be viewed from many different angles. The topics herein address a wide variety of the aspects of vision loss and will add understanding to the many ways that uveitic visual impairments can influence life and be constructively addressed. I highly recommend this illuminating journal for your attention and consideration.

Donald C. Fletcher, MD

The Frank Stein and Paul S. May Center for Low Vision Rehabilitation,
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Uveitis Interest Group



What is Low Vision and when do Uveitis Patients need Rehabilitation?

Only in a few uveitis patients the vision impairment is becoming so worse that they do develop problems with reading or have a dependent everyday life.

Prof. Nhung Xuan Nguyen and Prof. Susanne Trauzettel-Klosinski from the Low Vision Clinic at the University Eye Hospital in Tuebingen introduce this problem in the following article.

A macular edema is a swelling of the centre of the retina (macula) and is the main cause of reduced vision in chronic und relapsing uveitis (see [uveitis](#) 1/2005). The macula is the location of highest visual acuity. We need the macula for reading. If the macula edema exists for a longer period, the retina gets damaged (i.e. scaring) which may result in irreversible damage with possible disability to read.

Reduced reading ability means a severe lowering of the quality of everyday life. Patients are not independent any more. Furthermore, patients can lose their jobs or elderly patients have to move to a nursing home. Beside medical and/or surgical therapy rehabilitation plays an enormous role in providing the patients with low vision aids for the private, social and business needs.

Of more than 4700 patients, who were treated at our low vision clinic between 1999 and 2005, the percentage of uveitis patients was 2.5%. However, most of these patients were at working age, which makes sufficient aid for reading even more important.

The physiological principles of reading and the principle of low vision aids

A visual acuity of 0.4 (40%) and a sufficient reading field is necessary to recognise newsprint because when reading one has to fix a whole group of letters. Having a central scotoma (e.g. with macular edema or macular scar) the central fixation is covered by the scotoma and invisible. The patients have to look to one side of the central defect, they use another healthy retinal area

(eccentric fixation) (*Figure 1*). Because the resolution decreases rapidly with greater distance from the macula, objects are not sharp when they are fixated with more peripheral retinal cells. To solve this problem, texts and objects have to be magnified and the contrast to be improved (*Figure 2*).

The combination of eccentric fixation and magnification is the main basis for the adjustment of low vision aids in patients with macular disease. In most cases the reduced resolution can be compensated by higher magnification of the object, leading to a high success rate in uveitis patients.

Which low vision aids are suitable for the patients?

We would like to emphasise, that there does not exist a “universal” aid for all different visual tasks. Each magnifying visual aid is for a certain situation (e.g. for reading, for middle distances, for the far distances). So patients need different aids for different applications (like reading, seeing at distance, working in the household, computer, watching television). You need trained people to adapt the correct aid individually for an optimal and economic outcome. In the following article the different steps for the adaptation of a low vision aid for a uveitis patient are explained in detail.

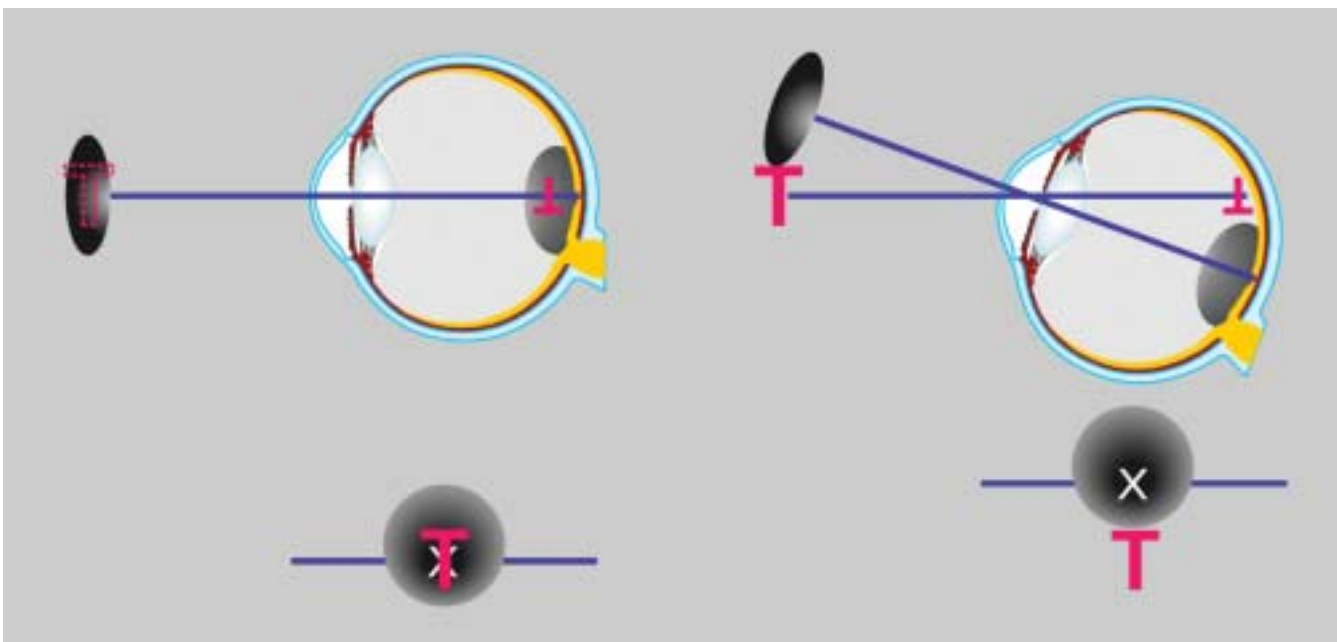


Figure 1:

Eccentric fixation: patients with central defect (central scotoma) need to use a peripheral retinal area close to the defect for seeing. They have to look “beside” the central defect.

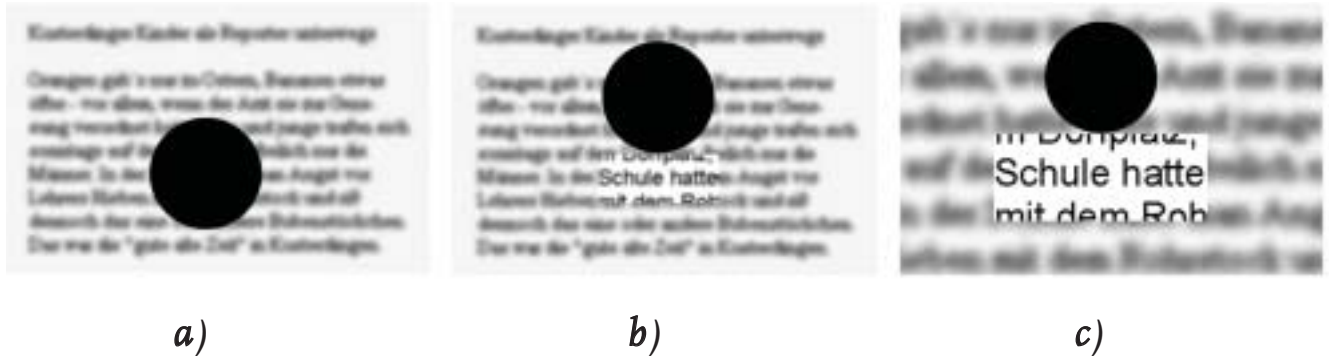


Figure 2:

Why do patients with macula edema or macula scaring have such a bad vision? For explanation we have to look how patients with central visual field defect fixate:

- a) the text is covered by the central scotoma when looking directly on the text*
- b) if the patient looks beside the defect (eccentric fixation) the letters remain blurred, the resolution is not sufficient to read the text. The peripheral retina has not such a good resolution as the macula*
- c) by magnifying the text with an optical aid, reading is now possible*



Ophthalmological Rehabilitation in Uveitis Patients - Practical Guidelines

When uveitis patients have poor visual acuity then the most optimal vision aids must be found for them. **Prof Nhung Xuan Nguyen** and **Prof. Susanne Trauzettel-Klosinski** from the Low Vision Clinic at the University Eye Hospital in Tuebingen recommend how to find the correct magnifying visual aid.

The choice of a magnifying visual aid

The optimal adaptation of low vision aids requires experience and enough time that allows us to find the appropriate low vision aid after carefully testing. Choosing an aid depends on both the degree of magnification and the type of task it is used for. In addition physical disabilities of the patient may play a role like shaking hands or the patients' motivation for reading.

For rehabilitation in low vision patients there is a huge variety of visual aids available. It is possible to divide them in 3 main groups (*Figure 1*):

1. optical magnifying aids:

- Different kinds of magnifiers (such as free-standing magnifiers – with and without light)
- Magnifying glasses
- Monocular telescope spectacles

- Telescope to use by the hand (e.g. for reading street names or bus-numbers)

2. electronic magnifying aids:

- Electronic device (mobile or stationary, with and without camera)
- Reading device

3. additional aids

- Edge filter glasses (contrast is enhanced and glare is reduced)
- Book rest
- Special lamps for reading for household
- Screen magnifier programs for the computer display

To choose the best magnifying visual aid medical, physiological and optical factors have to be considered. Therefore it is essential that patients are trained under professional supervision, how to

Title

handle and to use their low vision aids. The prescription of the final magnifying aid should take place only after a careful individual assessment. Handling of the aid and hand-eye coordination must be learnt in the clinic and at home.

Tips for the provision of a magnifying aid

Most uveitis patients suffer from a temporary visual reduction or a changing visual acuity depending on the grade of the inflammation. In our opinion an early provision of a simple magnifying aid like stronger reading glasses is useful to optimise the reading ability in the beginning of the inflammation or future recurrences. The use of a clip in combination with distant-glasses is a good way to maintain reading ability during an acute inflammation (*Figure 2*). There are also advantages in the use of a hand- or a free-standing magnifier. In patients with a permanent reduced vision magnifying glasses are commonly used. The provision of technically more difficult visual aids like telescope spectacles or reading devices is rarely necessary for uveitis patients (*Figure 3*). For children, simple bright field magnifiers or a monocular is helpful for reading at school. If the pupil suffers from a severe visual reduction with the need of a high magnification it is necessary to prescribe a reading device with a camera with sufficient magnification and large visual field for close up work at the desk, and also for distance work (to read the black board or projector, *Figure 4*). Older pupils often have to change the classrooms during the day; in these cases a laptop-based reading device is very suitable. For academic studies or working life an electronic reading device



Figure 1:
A selection of magnifying aids:
(A) optical, (B) electronical

with a camera and magnifying software are important aids. Very helpful for the work on the computer is also the use of a screen with rotary arm, so that the working distance can be changed. A study from our low vision clinic in Tuebingen showed a very high success rate in ophthalmological rehabilitation. Before the consultation in the low vision clinic in Tübingen only 16% of the patients were able to read regular book-print after an individual adaptation of a magnifying aid 94% were able to read. With the correct aid the reading speed (words/min) increased twice in average.

Social and professional rehabilitation

Besides the ophthalmological rehabilitation social and professional rehabilitation has to be considered in the care of low vision patients. For children early support is very important as well as consulting the School Service. For patients of working age it is important to assess the type of job, work place design and occupational retraining. Social and daily living rehabilitation is very important for patients and include provision of suitable travel passes, help contacting support groups and training in mobility and orientation (including use of white stick if necessary).



Figure 2:

The clip is put on the distance glasses to switch quickly from far distance to magnify near distance. The combination between this clip and the distance glasses are very useful for a temporary visual reduction in uveitis patients.



Figure 3:

An electronic device will be ordered normally when the magnification has to be higher than 6-times (+24 diopters). The text is magnified by a camera on the screen. The magnification can be adjusted up to 35-times. For a comfortable reading situation reading glasses in older patients are necessary.



Figure 4:

An electronic device with a camera for the black board for use at school. At the same time it magnifies the reading text (near distance) on the screen and the text on the black board (far distance).

Conclusions

Today the possibility and the success of ophthalmological rehabilitation for uveitis patients is very high. Not only the ophthalmologist but also the patient should have this possibility in mind. To obtain the most appropriate and the most economical adaptation, trained and experienced personal is necessary. With the care of a low vision clinic patients profit a lot from the rehabilitation so that their quality of life increases. The best care for a low vision patient consists of both ophthalmological examination and social and professional rehabilitation, aspects which will be discussed in this journal in other chapters.

Teaching Orientation and Mobility

For the development of the visually impaired child, orientation and mobility training is extremely important as there is a direct link between moving and learning.

Yvonne Clark from the Shetland Islands Council Psychological Service was firstly a teacher for physical education in primary and secondary schools. From there she moved into teaching physical education to children with additional support needs. It was while doing this that she encountered pupils who had visual impairments and she became very interested in this area of work, particularly teaching orientation and mobility. She now has the opportunity to work with a variety of children and young people with visual impairments. Recently, she has been doing additional training in Dublin, to gain a Diploma in Orientation and Mobility.

Why is Mobility that important?

“The area of orientation and mobility with its emphasis on movement, actually encompasses all developmental areas. For the young child who lacks visual input, movement through the environment may not occur naturally. Sight is a motivator for movement, and through movement young children learn about the world. Through the process of moving, young visually impaired children are able to interact with the environment and develop conceptual understanding that leads to growth in all other areas of development.”

Therefore we can see that it is by moving through the environment that the children gain an understanding of the world. They must be given the opportunity to experience this personally, and not second hand, from the information they get from others. Another important factor of independent travel is that it facilitates social interactions, enabling the young person to go shopping, attend youth clubs, and meet friends etc. When working with young people with visual impairments it is important to ask them what they would like to do. Often they are unaware of the support that is available for them to learn new skills, hobbies, and sports.

Early Focus (1994, page 80)

Mobility and Sports

If we look particularly at the area of sport for the visually impaired person, the benefits are immense; it improves fitness, raises muscle tone, and poor posture. It also improves coordination and spatial awareness, which are very important for success in mobility and orientation programmes. Also, unless young persons with a visual impairment has had the opportunity to attempt a variety of sports or activities, then they have no real understanding about the concepts of games, e.g. the rules. They need to understand the terminology used in sport and be familiar with the equipment. This also allows them to enjoy discussing sport with friends. If the young persons have a newly acquired visual impairment, or has a deteriorating eye condition, it is important that they can continue to participate in sports they have participated in previously and enjoyed, and this can be done with support and with some adaptations to equipment if necessary.

Also Family members need teaching

Teaching sighted guide skills (when required) and doing vision awareness training with members of the family, peer group members, and any one involved in supporting the young person is also extremely important. This will increase the opportunity for the young person with a visual impairment to participate and be integrated into the club or group. This in turn will promote self esteem and ensure that the young person with a visual impairment makes the fullest use of their abilities.

References

Pogrund R.L, Fazzi D.L, Lampert S, Tanni A (1994)

Early Focus

American Foundation for the Blind

Sports and Visual Impairment

Can partially sighted, or blind, children and adults, participate in all sports? Which sports are unadvisable? Dr. Georges Challe from the Pitié-Salpêtrière Hospital in Paris, Member of the Medical Committee of the Disabled French Federation and Medical Director of the International Blind Sport Association describes the legislative aspect and how we deal with the benefits and the risks of sports practice for visually impaired people. He will then cover important aspects of competitive sport by visually impaired people.

Sport for sightless and partially-sighted People

Sports can give great benefit to everyone and in the visually impaired can be a source of development, a pleasure and an improvement in their self-esteem. Actually, the right to practise sports is now mentioned in French law. From a legal point of view, persons considered to be blind or sightless, if their visual acuity is lower than 1/20 (categories 3, 4 and 5 of the WHO). Partially-sighted people (categories 1 and 2) are those with an acuity going from 3/10 to 1/20.

For sports, there is a fundamental difference between those whose visual impairment has been present from birth and those whose vision impairment occurred later in life. Undertaking a sporting activity will be much easier in the latter, because we can refer to precise visual images of the activities involved. Also, there are important differences between people who have

central or peripheral visual field loss. A central defect ("scotoma") resulting in central vision loss can cause less difficulty when learning a sport than if there is peripheral vision loss.

Reduced visual acuity must not prevent someone from becoming a good sportsman. Looking at sport participation by the visually impaired causes us to rethink the way we look at sport and low vision. Watching high-level visually impaired sportsmen teaches us that their visual strategies vary from one to another. Some examples follow:

- In **Archery** there is an archer who fires without optical correction of his myopia of one dioptré. Another archer is known to take part despite his large scotoma.
- I presented a video of "**Blindfootball**" to medical students and nobody realized that it involved visually impaired people having less than 1/10 of visual acuity! Despite their very poor vision, all of the

participants had an excellent peripheral field of vision.

■ In *Athletics* a sprinter competed at such a high level it brought doubt on his level of blindness. In this case the high performance could be partially explained

because he was at a very high standard at the time he lost his sight.

Beyond these impressive examples, the daily reality of sports for the visually impaired is more difficult.

How accessible is Sport to visual impaired People?

Practice of sports and physical activities at school

Physical activity and sports education is compulsory in most countries in the Western World. A child can be exempted on medical grounds but requires a certificate that does not exceed the current school year. This also has to indicate the degree and type of visual impairment. For participation within a sports association or club a certificate is required to show that there are no medical contra-indications. Most children with impaired vision are exempted from sports at school because of fear by their parents, or because of a lack of facilities or of a means to supervise them.

Sporting activities

Almost all sports can be practised by visually impaired people with one or several adaptations, like Rowing (requires a guide), Skating (requires a guide), Diving (the divers are accompanied by instructors who give them tactile signs under the water. There are specific types of dives for the visually impaired person), Tenpin Bowling, Water-Skiing, Climbing, and also the practice of certain martial arts, like Karate.

Are there Sports which should not be performed by visual impaired People?

Risks for doing sports can result either from the visual impairment or the eye condition. Both may increase risks of worsening in falls or blows. Some sports are considered impossible for blind people or severely impaired vision: Badminton, educational Boxing, Sand Yachting, Hockey, Rugby, Tennis, Table Tennis, Volleyball, Water Polo, and Solo Triathlon. Some sports may be practised with a lot of adaptation: Basketball, Biathlon, Handball, and Fencing. Some other sports can be practised with few or no adaptations even by blind people.

There are countless adaptations that can be made and these can often rely upon the ingenuity of supervisory staff. The use of bright colours, high contrast, textures and changing the speed of some games are examples of things that can be changed to adapt the sports. Professional staff such as optometrists can be brought in to help.

The main examples of eye conditions that cause risks in sport are: the effects of retinal disease of premature babies, detachment of the retina, retinoschisis, high myopia, aphakia (the absence of the lens of the eye) or pseudophakia (original lens substituted by an artificial lens), or generally eyes which have undergone surgery. Glaucoma surgery

remains a problem in term of the bulbar fragility; but it does not constitute a contra-indication in sports practice. To quantify this risk it is absolutely necessary to ask the opinion of an eye specialist. It may be difficult to assess the combined risk due to the specific eye condition and increased risk of accidental eye trauma due to low vision.

Often only social conventions and 'stereotypes' that prevent many of the visually impaired from thinking of doing, and being offered to take part in many sports. In fact, logically there are often no reasons why sport can not be played with some "common sense" adaptation.

Competitive sport by visually impaired people

Competitive sport for the visually impaired is mainly made up of the Paralympic games where there are only a limited number of "Paralympic" disciplines. Several disciplines are not represented in Paralympic games that are nevertheless specific for the impaired vision people (Toreball notably).

Brief History of Sport for people with disabilities

In 1944 Sir Ludwig Guttman, a neurosurgeon, created a Rehabilitation Centre for the surviving airmen of the World War II who were traumatized. Sport was integrated into the program of re-education. This sport, then leisure activities, became competitive and in 1948, with the Olympic Games of London, the first national competition for handicapped athletes was organised. In 1952 Dutch athletes participated in the first International Games of Stoke Mandeville. In 1960 the first Paralympics in Rome took place. It grouped together athletes with complications of brain injury. In 1976 in the Games of Toronto, visually impaired people participated for the first time.

Classification of Competitive Sports

The objective of the classification is to collect in the same group persons of similar visual impairment. Visually impaired sportsmen and women are referred by the letter B (blind) and classified in 3 different categories, depending on their visual acuity and their field of vision:

B1 - No light perception in either eye up to light perception but inability to recognise the shape of a hand at any distance or in any direction

B2 - From the ability to recognise the shape of a hand up to visual acuity of 2/60 and/or visual field of less than 5 degrees.

B3 - From visual acuity above 2/60 up to visual acuity of 6/60 and/or a visual field of more than 5 degrees and less than 20 degrees.

Title

There are various disciplines in **Skiing**. Alpine skiing includes descent, giant slalom, super-giant slalom, slalom. It requires a megaphone for **B1** and **B2**, or a transmission radio. A guide is necessary for the three categories. In Nordic skiing the runner has to follow a track. There are also some interesting team sports at the Paralympics. Besides **Indoor Football**, a special sport is **Goalball**. It will be played by a team of three players and three replacements that is played with bandaged eyes. It will be played with a ball of 1250 g with a bell

inside on a field of 3 zones, each 9x3 meters, the team field, the throwing zone, and the neutral zone. With the help of orientation ropes, touched by the players, the three players recognize where they are. Goals are scored by throwing the ball by hand into a goal cage of 9 x 1.30 m. It requires a large degree of concentration during the 2 x 7 minutes of play.

Toreball has the same principle but it is not a Paralympic discipline. A rope is used with "sound" marks (bells) tied in at a 40 cm height. The ball contains



a small little spherical bell inside. The purpose is to send the ball with the hand below ropes in the opposite goal.

Besides *Archery*, *Shooting* at 10 m in various positions will be performed: A sound of variable frequency and intensity according to the position of the target guides the marksman who can also use a sighted guide. Three categories of **B** compete together.

Watersports is topped by *Swimming*. A person warns the swimmer of the

approach of the turn by touching their shoulder using a sponge hung on a pole. Also an electronic device if available can warn them. *Sailing* requires a guide.



Title

Besides *Weightlifting* other disciplines are *Judo* (with specific groundsheets which are “tactile”, the fights are started by “Kumikata” that is hands holding the opposite kimono) and *Equestrian*. Here only the athletes in the category **B1** and

B2 are allowed to participate. It is considered that horse riding disciplines do not constitute a disability for people whose visual acuity is better than 1/30. They compete in the mainstream events.



The Competition Organizers

The International Paralympic Committee (*IPC* - <http://www.paralympic.org>) is the global governing body of the Paralympic Movement. The IPC organizes the Summer and Winter Paralympic Games, and serves as the International Federation for nine sports, for which it supervises and co-ordinates the World Championships and other competitions. The IPC is committed to enabling Paralympic athletes to achieve sporting excellence and to develop sport opportunities for all persons with a disability, from the beginner to elite level. In addition, the IPC aims to promote the Paralympic values, which include courage, determination, inspiration and equality.

The IPC is an international non-profit organization formed and run by 162 *National Paralympic Committees (NPCs)* from five regions and four disability specific *international sports federations (IOSDs)*:

- **CPISRA:**

Cerebral Palsy International Sport and Recreation Association

- **IBSA:**

International Blind Sports Federation (<http://www.ibsa.es/eng/>)

- **INAS-FID:**

International Sports Federation for Persons with Intellectual Disability

- **IWAS:**

International Wheelchair and Amputee Sports Federation

Conclusion

Everyone should have the right to sport, and visually impaired people often do not have large technical difficulties in terms of adaptation. Sporting disciplines that seem at first sight inaccessible to the visually impaired are only so because of conventions and hesitancy. In children, their impaired vision and participation in sport should be encouraged but must be decided after discussion with the physical educational teacher, the child, the parents, and the school doctor.

All cartoons by

Michael Mauser, Rottenburg, Germany

Literature in Largeprint – A Project of the Future

In cases where uveitis involves the macula, the ability to read can decrease rapidly. This means a loss in quality of life for many patients. Mrs. Kristina Lindenthal from Vienna reports about publishers who are able to help such patients to read more easily.

The European population is getting older, a fact that creates new challenges for politics and economy. Book publishers have to react to such a change of demographics. To follow the needs of mainly older people, but also of people with low vision, book publishers like Ueberreuter in Austria have started a section with books which are printed in largeprint.

Until recently only the negative aspects of an aging society have been considered. But now a positive campaign has started to improve the image of the “New Olds”. The market has recognized the elder generation as an important economic factor. Travel for seniors, dating agencies for new partners and age adapted portable telephones form a part of a broad program for older consumers. Prerequisite for this change is a new self-image of the older generation: they are more dynamic and more versatile than in previous years.

As a consequence the group of publishers has discovered the target-group of “Old Ager”. An approach to this group, which likes reading and spending money, is not only by themes, but also by products, which are especially adapted to persons of a certain age. There will be more information about the reading process itself, which has been neglected for a long time. What conditions and criteria are necessary for old people to read effectively and without interruption? These are, of course, also important criteria for people with poor vision. Following a study of the German Book Publishing Industry from 2005, 60% of readers report that the aspect of “readability” is an important to very important criterion for purchasing a book.

Book editions with largeprint reflect today’s demands. Besides audio books, books with largeprint represent an ideal solution for people who love to read, but have problems or probably are not able

to read the normal letter sizes. This may be due to age or due to ocular disease. Compared to the normal size of the letters in a paperback, letters in a largeprint book are doubled in size (*Figure p.29*). Besides size and type additional crucial factors like type of paper and format play a major role in the creation of these books. Books in largeprint should allow the reader to enjoy reading for long spells even when the lighting conditions are not perfect. It is important to avoid rapidly tiring the eyes, leading to stopping reading after only a short time.

The idea for this visionary project came from the US publisher Thorndike which is now the most important publishing group in English speaking countries with 1500 new books a year. In contrast to publishers in Germany and Austria the program of this group is not primarily for older people. "Largeprint is for Everyone!" is the slogan of Thorndike's program, showing their support of acquisition of reading skills especially for younger people. Following the results of an American study, books with largeprint improve the speed of reading and therefore reading success and pleasure of reading. This results in a teaching aid not only for first readers, children before or just at the start of school. Facing the alarming increase of illiteracy in the industrialized countries, books with largeprint

may be able to help socially and visually impaired and elderly people to participate in an important part of cultural life. Public libraries are suited to provide largeprint books especially as older people, children and adults are major clients. "Libraries in various European countries have already realized the interest of their readers in largeprint books", Fritz Panzer claimed, the director of Ueberreuter Publisher. Many libraries have already established special sections for largeprint books. The publishers have increased their largeprint books in response to requests from their readers for a more diverse variety of topics and interests. This is most welcome. Therefore, patients as well can profit from the growing market of books created primarily for a different group.

Literature in largeprint – a project with a future, because much more is possible! The group of readers of such books has just the same range of interests as anyone else. There is an urgent need for more initiatives in this field.

For further Information:

www.ueberreuter-grossdruck.com

Webshop: shop.ueberreuter.at

www.galegroup.com/thorndike

Random House Large Print

<http://www.randomhouse.com/largeprint/>

Random House has a book club named “*Doubleday*”, besides other reasons as well regarding the topic of largeprint books

http://www.doubledaylargeprint.com/doc/full_site_enrollment/fse_homepage.jhtml

One of the leading suppliers of **large print books in the UK**, including best seller lists

<http://www.largeprintbookshop.co.uk/index.php>

National Library for the Blind, a public resource in the UK

www.nlb-online.org

For the French edition:

France (Livres en grands caractères)

Éditions de la Loupe

<http://www.editionsdelaloupe.com/>

Editions A vue d'oeil

http://www.lireengros caracteres.com/gros_caracteres.htm

»Stellen Sie sich vor?«
 »dass alle Schulden in der Welt zu
 werden müssen und sofort bezahlt werden müssten!
 Was würde unter den gegenwärtigen Verhältnissen
 geschehen?«

Ich gab die selbstverständliche Antwort, dass
 ich dann ein ruiniertes Mann sein würde, worauf
 er von seinem Stuhl aufsprang, mir meinen gewohn-
 ten Leichtsinn, der es ihm unmöglich machte, ir-
 gendeinen ernsthaften Gegenstand in meiner Ge-
 genwart zu diskutieren, vorwarf, wütend aus dem
 Zimmer stapfte und die Tür heftig ins Schloss
 warf, um sich für die Loge umzuziehen.

Ich war also endlich allein mit Gladys, und der
 Augenblick, der mein Schicksal entscheiden sollte,
 war gekommen! Den ganzen Abend hatte ich das
 Gefühl eines Soldaten, der das Signal erwartet, das
 ihn auf einen verlorenen Posten schickt, ein Ge-
 fühl, in dem die Hoffnung auf den Sieg mit der
 Furcht vor der Niederlage abwechselt.

Sie saß vor mir, ihr stolzes und zartes Profil hob
 sich klar gegen den roten Vorhang ab. Wie schön
 sie war! Und doch wie fern! Wir waren bisher gute
 Freunde gewesen, recht gute Freunde, niemals
 aber war es mir gelungen, über jenen Grad von
 Kameradschaftlichkeit hinauszukommen, wie er
 etwa zwischen mir und einem Kollegen von der
 Abteilung bestand.

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Figure

Letters in a largeprint book are doubled in size.

Low vision and playing piano

People with low vision tend to concentrate on their other senses such as hearing. When vision is worsening, some patients want to learn to play an instrument like piano. How realistic is such a wish?

*Elke Altpeter, MD, ophthalmologist at the University Eye Hospital in Tuebingen, talked with the concert pianist and musical educator **Wei Tsin Fu** about these possibilities.*

The person:

Mr. Wei Tsin Fu was born on the island of Java in Indonesia. He learned to play the piano since the age of 10 years. Having studied mathematics and theology in Indonesia, he moved to Germany to study the piano for 27 semesters receiving education from 20 of the greatest pianists in Europe. He concentrates on genetic and brain research and its educational impact. By linking the left and right hemisphere of the brain, it is possible to achieve success easily. By this principal he developed his well-known training method for piano, called “Snowman’s Dream”.

In 1989 Mr. Wei Tsin Fu founded the Music Academy in Tuebingen, where he teaches the piano and is connected via web-camera with his worldwide 23 music academies (International Brain Academy) where his method is practised.

What was your intention to teach low vision patients to play the piano?

Playing music can make your life so rich; it’s a real pleasure and contributes to your personality. If a student is not able to play a certain music piece, the teacher must have chosen the wrong method to teach the student correctly. Often teachers have to find individual solutions for students with physical and mental disabilities. The teaching atmosphere should be positive and relaxed. I have seen disabled students who started a new life with the help of music.

What is your strategy to teach low vision students?

The first step is to differentiate reading notes from playing the piano. The student is playing the piano without notes to get to know the instrument and develops a relationship to the piano, using the keyboard like a map.

Orientation is important. With simple and successful exercises the student learns playing piano. First he learns the black keyboards as “twin or triple from Africa” and the white triplets and quadruplet. Then he learns to find all “C’s”. The main difference to the traditional teaching method is the order: chords, then intervals and finally single tones. This is in accordance with results from brain research about the learning strategies of the human brain, but it is in contrast to the traditional teaching method.

Parallel to this the student learns to read the notes without the piano with the help of figures like “Room-Tree”, “Line-Tree”, “Caterpillar”, “Snowman”, “Snowman with Hat“, “Snowman on Skateboard”. The principle is based on recognising the notes and the sequence. Additionally the notes are magnified by copies and printed on a yellow coloured or beige paper. Especially for low vision students it is not necessary to see each single note and name it. The strategy is to develop a “feeling” or “sense” for the sequence of the notes and the chords and to keep the orientation on the keyboard. It is necessary to have fun and laugh during the learning process. Especially low-vision students should not be frustrated or over-trained by recognising the single notes. The next step is to play the piano while reading notes.

The principle of this teaching method is to simplify thinking with the effect that the students are able to recognise the notes and play easily without playing more than they can handle. They learn to read the notes as a picture of a landscape. In a split second the “landscape” of the notes is detected with ease, which is even more effective than reading a text. Traditionally notes are transferred in “names of notes”, but why? Students with low vision enjoy the “landscape of the notes” in contrast to putting the single notes together.

What is your method to teach blind students to play the piano?

On one hand there are students who were able to see in the past before they became blind and most uveitis patients belong to this category. They know what a piano looks like with its white and black keyboards or they have even read notes before. In contrast to this there are students who are born blind and they have to feel for the piano and get to know it.

In the lessons the right and left hand are trained separately and played to the student. Most students have an excellent sense of hearing. Especially for blind students the orientation on the keyboards is necessary. They learn to think and feel in different distances between the keyboard. They are trained by our auditory method of chords

Title

(smiling, sorrow, anger) and intervals (Chinese, European, Accident etc).

The most difficult thing in teaching a blind student is to teach the position of the hand on the keynotes which should be “loose”. Most blind students have problems with holding the hand “loose” as they have a very stiff posture. We developed exercises to learn “loose” at home in a “safe” environment.

A 9 year old boy in Sumatra was born blind and learns the piano since he was 2 years old and just recorded “Alla Turca” by Mozart. Soon this will

be seen on the website of Mr. Wei Tsin Fu. Other students with Down’s Syndrome were able to play Beethoven’s “For Elise” in concert after 8 months of learning the piano. Children and teenagers with autism have made so much progress that the Australian government pays for the piano lessons.

After 2 1/2 hours of interview which also included a private piano lesson for me, when we practised the different exercises and training methods I understand how fast and successful they are. Thanks to Mr Wei Tsin Fu, and for all of you who now want to play piano, have fun and a lot of courage.

For further information:

www.musikfoyer.de | www.musikakademie-uri.ch | www.musicacademy.com.au



Piano Player painted and reproduced by permission of Esref Armagan

Painting and Low Vision

*Low Vision can obviously lead to all sorts of both practical and psychological problems and artists who are visually impaired and wishing to paint may be expected to experience all sorts of difficulties. **Phil Hibbert** from UK analyses these problems and describes how both well-known painters, such as Edgar Degas (here supported by **Jeanne Hérault** from France) and Claude Monet, and also modern living artists solved these problems and how they were able to create a new vision of art.*

Does low vision lead to bad art?

It may be true that Low Vision creates multiple problems for painters, but hopefully this article will demonstrate that with a positive outlook Low Vision may just make things different, but not necessarily ‘worse’ or more limited. Looking at how some artists have approached their painting it seems as though the most important things are **the ability to adapt** and **a positive attitude** to see the possibilities open to them. There are many different types of vision loss associated with uveitis. Each will have their own way of challenging the artist. There are people who are existing painters who then lose their vision and then, interestingly, there seems to be a group who take up painting only after they have lost their vision. It is this group which may tell us a lot about the nature of vision loss.

Why would anyone take up painting once they had lost part or all of their vision?

Some artists who have done this describe that they still retain a large ‘visual sense’ and will picture things in their mind. One artist explained that there were pictures in his mind and he just had to ‘get them out’. The following stories of different artists hopefully show that there is a lot to be learnt about the nature of vision and its loss.

I wish to look here at how some artists, some very famous, have coped or adapted to low vision and how it has changed their style or technique. Two famous artists who experienced low vision at some point in their lives were Edgar Degas and Claude Monet. These artists wrote about their failing vision and appeared to suffer badly at times. This may be because their lives were so passionately devoted to painting and they had a lot to lose. Also, in their days,

there was often little that could be done to restore their vision and so it would have been more difficult to be positive about their plight. However they both adapted to their low vision and it is fascinating to see how their style and techniques changed with as their vision diminished.

Edgar Degas (1834 - 1917)

Degas developed his vision problems relatively early on, at least by his thirties, and certainly by his 40's he had central vision problems. He also suffered from photophobia. A definitive diagnosis has never been confirmed but he certainly had a retinal disease and the term 'chorioretinitis' (posterior uveitis) has been reported amongst others. Degas suffered greatly psychologically as a result of his vision loss and yet still remained very creative. His suffering could partly be explained by a fear of blindness. He was very moved by the tragedy lived by his step-sister Estelle who lost the vision of the left eye, then right, at age 38. There was also little prospect of a cure for his problem.

He had at various stages problems with colour and contrast sensitivity and scotoma affecting his central vision. As Degas' vision deteriorated his painting changed in different ways. Due to his photophobia, he could not tolerate to paint outdoors and so became the only Impressionist painter to paint mostly

indoor scenes. He moved from using a brush for oil paints to his finger and then turned from oil to pastels which may have been easier to work with. His colour use became bolder, his strokes were progressively bolder and wider and the detail decreased. Outside painting Degas also moved into sculpture and photography.

During an artist's life changes in style and technique would be expected regardless of eyesight, and so it is difficult to say for certain how many changes in Degas's work were caused wholly by his deteriorating vision. Although there is much written about Degas' art and his vision, the question of whether low vision can enhance or improve artistic vision is still open. Some describe the later works as limited or coarse, yet Renoir thought much of his later work and is attributed as saying "Had he died at 50, he would have been remembered as a good, competent artist, nothing more."

Claude Monet (1840 - 1926)

Claude Monet suffered from cataract and his vision only deteriorated as he got older. For Monet, his cataract caused a decreased perception of colour intensity. It is this change in colour perception which probably gave Monet more problems than any failure in his visual acuity.

As he passed 65, when his vision started to be affected, the colours in his work shifted. The whites and the greens would become ‘muddier’ and shift more to yellows and purples. He had most trouble with reds. This colour problem fits the well known ‘yellowing’ of vision due to cataract. Again, like Degas, whether Monet’s vision problems actually enhanced his work is open to argument. He certainly threw out some work done in between the period of having cataracts and having one of them removed, after which he had a partial improvement in vision. Monet’s work progressively changed, not only in its colour but also became more abstract. Some consider his massive and nearly abstract paintings of water lilies to be some of his best work and some of these were done when he had very poor vision.

It would be useful now to look at how, in recent times, some artists with low vision have adapted to painting. Hopefully we will see how much more can be achieved than we could imagine. One artist in particular serves to demonstrate how rigid we can be in what we expect to happen when someone has little or no vision.

Esref Armagan

Esref Armagan is an artist who has been totally blind since birth and so has not even any conventional visual memories. Yet he has become an accomplished

artist who produces drawings and oil paintings which display light, shadow, perspective and colour which are all represented as a sighted person would see them. Armagan is now very well known and has exhibited his work widely; including painting Bill Clinton’s portrait. He draws his subjects by having earlier explored them by touch and then uses a special drawing board draws the outlines of his work making raised “puckered” edges which he can then feel. For painting on canvas, he uses a different technique: he paints using his fingers to put on a thick layer of acrylic. He uses only 7 colours lightening and darkening them with white and black and mixing colours for different effects. Recently he has started using an air-dry clay to make outlines to make it easier to follow. He also works from photographs which he does for his portraits.

He agreed to be the subject of a detailed study to determine what was happening in his brain when he painted. Dr. Alvaro Pascual-Leone from the Centre for Non-invasive Brain Stimulation at Beth Israel Deaconess Hospital in Boston used brain scanning techniques to measure the activity in different parts of Armagan’s brain while he was performing different tasks. It has already been established that when sighted people try to imagine scenes, faces or a painting, for example, then the same part of the visual cortex in the brain

used for seeing things is activated but to a lesser degree. Painting is like a lesser form of 'seeing' without actually seeing. The interesting thing that was found with Armagan was that this same lesser activity was found when he imagined scenes etc. But when he actually drew a coffee cup, the visual cortex became as active as a sighted person's who was seeing the coffee cup 'for real'. It seemed that Armagan was much closer to 'seeing' than we could ever think of a completely blind person. Armagan obviously has mental pictures of things. This mental picture is usually referred to as the "mind's eye". It was always thought that a person who had never had sight would not be able to have this "mind's eye". However Armagan has shown that this is not the case and begs the question how do we build up these mental images? In Armagan's case it seems as though touch and description can be very powerful in building these mental images. Pascual-Leone argues that we use all our senses to build up these mental images especially touch but because sight is such a dominant sense, we don't really appreciate the importance of the others.

The work of Armagan could be explored in great depth and has been, but for the purposes here, suffice to say that anyone who has developed low vision for whatever reason would benefit from

realising the amazing flexibility and fluidity of the brain and how it is capable of adapting if we give it the chance. It could be said that Esref Armagan's case is rather extreme. There are plenty of other examples of how people who have taken normal vision for granted have lost all or a significant part of their vision and have taken up painting. As mentioned before, there seems to be a strong desire to paint to 'release' these mental images that we still have inside us. This aspect of painting must not be overlooked. We too often judge painting from the viewer's perspective or from a monetary value. That is not to say, of course, that the work of painters with low vision will not be valuable in this sense, as the argument about Degas shows.

Neil Harbisson and the Eyeborg

A colour blind artist who could only recognise black and white shades has learnt how to paint with a full palette by "hearing" the hues he cannot see. Neil Harbisson, 25, from Spain, has achromatopsia, a rare condition causing complete colour blindness. He moved to the UK in 2003 where he was been fitted with a device called an Eyeborg, which was developed for him by an innovative software company. The Eyeborg converts 360 colours into different sounds via a small digital camera. Surely this is

a good example of how strong the 'desire to paint' can be and also how there seems to be no limits to how we can adapt.

Barrie Goodfellow

Barrie Goodfellow from the UK has been vision impaired since when he was 11, and took up painting after retiring from running a successful business once he was registered blind. He started painting with water colour and later moved to acrylic. Most of his paintings feature seascapes, fishing boats or some element of water that are always captured in his mind when out walking. He has adapted to painting by using a lot of very simple but effective methods. It is clear that he had a positive 'problem solving' approach and was not put off by practical difficulties because he wanted to paint. By careful choice of subject matter, and by the use of bold colour and contrast, his painting is very much from the heart and he is keen for his art to be appreciated by visually impaired people. He helps other people to develop their painting skills and can give good advice on adapting painting techniques to low vision. Examples of Barrie's work can be seen on the web pages below.

Hopefully this article helps to show us that low vision does not necessarily close doors. Our brain is very good at making detours and adapting if we help it to by

adopting an open mind and a positive attitude.

References:

Cara Feinberg, Boston Globe jan 2006
New Scientist magazine, 29 January 2005, Issue 2484
thanks to Joan Eroncel, Mr Armagan's manager

Barrie Goodfellow:

<http://www.lowvisionart.org/>

Esref Armagan:

www.esrefarmagan.com or his older site www.armagan.com



Windmill painted and reproduced by permission of **Esref Armagan**

Social Rights and Support for People with Low Vision

People with Low Vision as a result of uveitis have important questions, apart from the medical ones, about their eye condition such as: What vision aids am I entitled to? What help is there for 'reduced earning capacity'? And how do I apply? What level of low vision qualifies me for benefits, for example for public transport? **Lothar Weisel**, the expert for social problems from the German patient interest Group (**DUAG**), developed the following excursion into the social rights of patients with low vision, **Phil Hibbert** adapted this completely to the British situation.

“All human Mankind are equal regarding their Rights”

You will find this sentence in the *European Convention of Human Rights*, and it specifically includes disabled people. In the UK the *Disability Discrimination Act* (DDA) from 1995 aims to end the discrimination that many disabled people face. This Act has been significantly extended, including by the Disability Discrimination Act 2005. It now gives disabled people rights in the areas of:

- employment
- education
- access to goods, facilities and services (including larger private clubs and transport services)
- buying or renting land or property (including making it easier for disabled people to rent property and for tenants to make disability-related adaptations)

- functions of public bodies (for example issuing of licenses)

The Act requires public bodies to promote equality of opportunity for disabled people. It also allows the government to set minimum standards so that disabled people can use public transport easily.

There are major differences in systems of Health and Social Care in different countries. In Germany and the UK, probably the biggest difference is that Insurance companies are much more involved in Germany whilst in the UK the government run departments of Health and Social Care are mostly involved.

“Disabled Persons” and “Severely Disabled Persons” What is the Difference?

The *Disability Discrimination Act* (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

What does this mean for vision impaired people? There is a registration system in the UK and the decision on whether a person can be registered is made by a Consultant Ophthalmologist.

To be registered as **severely sight impaired (blind)**, sight has to fall into one of the following categories:

- Visual acuity of less than 3 / 60 with a full visual field
- Visual acuity between 3 / 60 and 6 / 60 with a severe reduction of field of vision, such as tunnel vision
- Visual acuity of 6 / 60 or above but with a much reduced field of vision, especially if a lot of sight is missing in the lower part of the field.

To be registered as **sight impaired (partially sighted)** your sight has to fall into one of the following categories:

- Visual acuity of 3 / 60 to 6 / 60 with a full field of vision
- Visual acuity of up to 6 / 24 with a moderate reduction of field of vision

or with a central part of vision that is cloudy or blurry

- Visual acuity of up to 6 / 18 if a large part of your field of vision, for example a whole half of your vision, is missing or a lot of your peripheral vision is missing.

It may be useful to comment at this point that the registration system has fundamental problems, because many people with significant vision problems do not enter the system and the system can be slow, delaying the urgent help needed for people who have developed a sight problem. The whole system has been reviewed in the UK and major changes have been proposed. Already the role of Optometrists is being expanded to assist in both assessing and treating Low Vision and some eye conditions.

What are the Advantages of being a registered Severely Disabled Person?

The advantages may depend on the level of disability (partial or blind registration – see above), and although some help is not dependent on it, being registered will be an advantage in gaining most of the benefits.

The following areas will bring advantages:

- Disability Living Allowance (available whether or not you are registered)

- Attendance Allowance (if you need someone to visit to help with daily living like dressing, washing etc.)
- Possible funding for education
- Concessions on transport, tax credits and your television licence
- Disabled parking permit
- Blind Person's Tax Credit
- Access to Work, a scheme run by the JobCentre Plus, a Government employment agency (special adaptation, equipment etc. available to retain job).

The Welfare System of Benefits in the UK can be very complex and bureaucratic. It is strongly recommended that advice is taken on how to find out which benefits apply and how to apply for them. Large voluntary organisations such as “The Royal National Institute for the Blind” (RNIB) and “Action for Blind People” will give professional advice on these matters (see contacts at end of article). These organizations report that many people they consult with are on the wrong benefits. This is in large part due to the complexity of the benefits system.

There can also be a large variation between different areas of the UK. For example, people who are partially or blind registered in Scotland get many more travel concessions than those in England. In London the travel concessions are also better than in the rest of England.

What are the Goals of the Law for disabled People and their Rehabilitation?

In Germany these goals are defined in the following way:

- Removal or reduction of the disability
- To reduce the complications and effects of the disability (e.g. with the help of visual aids)
- Minimise the factors leading to reduction in earning capacity
- Participation in work fully, given certain restrictions
- Promotion of personal development (including education and leisure)
- To establish an individual and independent way of life, e.g. by courses for orientation and motility, allowing independent travelling by feet, bus or train.

In the UK, there is broad agreement but the goals are not specifically laid out as for Germany.

Rehabilitation

What types of Rehabilitation are available?

Rehabilitation can be divided into:

Medical rehabilitation

- **treatment of the condition as out or in patient and assessment of vision, leading onto use of vision aids.**

Social and Work related rehabilitation

- **one of the most important aspects for the patient is the protection of earning capacity and adaptation of the job type or workplace. Even if the vision problems can be largely overcome, this rehabilitation may still be required.**

The Government Departments of Social Service are responsible for assessing the needs and providing for the rehabilitation of people with disabilities. However a lot of the rehabilitation services are provided by independent charitable organisations such as “The Royal National Institute for the Blind”, and “Action for Blind People” to name just 2 of several.

How do You apply for Rehabilitation?

Anyone who thinks to have a vision problem can ask for “An Assessment of Need” by their local Social Services

Department, which is part of the local government. There is no need to be registered to do this. How this works can vary between England and Scotland.

1. The ‘High Street’ Optometrist (Optician)

One can ask for a “*Low Vision Leaflet*” (LVL), which can be filled in and sent to Social Services to ask for an assessment. The Optometrist can refer the person to the local eye clinic to be seen by a Consultant Ophthalmologist or also to a low vision clinic, to see an Optometrist specially trained in low vision work. Some local Optometrists are now carrying out this work in the community.

2. The Hospital Eye Clinic

If the Optometrist did not give the LVL form or if the person is at the Hospital Eye clinic already, then with the person’s agreement eye clinic staff can fill out a “Referral of Vision Impairment” (RVI) form. This form will:

- **tell Social Services about the person’s situation**
- **request an assessment of their need for support**
- **state how urgently they think they require help, so they do not have to wait until the end of their treatment at the clinic to be referred.**

3. Self Referral

Anyone with vision problems can contact the Social Services directly. They

may do this with the help of a local medical GP, a voluntary organisation, or a relative, for example.

The “*Assessment of Need*” should assess at least:

- Practical help in the home
- Getting a radio or television
- Using library services
- Using leisure and education facilities (including arranging transport)
- Aids and adaptations to the home
- Taking a holiday
- Meals in the home or elsewhere (such as at a day centre or luncheon club)
- Getting a telephone and any special equipment needed to use it.

As a result of this assessment then the necessary support should be set up and carried out by:

- Rehabilitation and mobility worker
- Social Worker
- A combination of a carer (relative or friend) and trained staff. This also allows for the person with low vision to arrange for their own support with the help of a “direct payment scheme”, where the Social Services would pay the person to provide vision services of their own choice.
- Community Optometrist operating a low vision service (not widespread in the UK)

Many people with sight problems however do not access “official” services. This may be because they do not know they exist or they prefer to “help themselves”.

But there is a huge amount of support which people with low vision can source themselves. There are voluntary organisations which can provide:

- Resource centres which supply all sorts of aids for daily living, from simple things like watches and stickers to high tech closed circuit televisions (CCTV)
- Employment and training resources
- Emotional support, either through counselling or putting people in touch with others
- Large print, or audio books or transcription

The most important thing for anyone who develops low vision is that they get directed to the best help *as soon as possible* because it is clear that any delay can significantly interfere with the process of adaptation and building up a very positive outlook.

A global initiative “*Vision 2020: The Right to Sight*”, has been developed in response to a World Health Assembly resolution in 2003, which urged the development of national plans to tackle sight loss.

Hopefully this will mark an improvement in the social rights and services provided to people with low vision in all countries.

Links and Contacts in UK

Social and Welfare Rights **Action for Blind People London**

14-16 Verney Road, London, SE16 3DZ, Tel: 0800 915 4666, Fax: 020 7635 4829
benefit.check@actionforblindpeople.org.uk

Royal National Institute of Blind People

105 Judd Street, London, WC1H 9NE, Tel: 020 7388 1266
www.rnib.org.uk



Fruit and trees painted and reproduced by permission of *Esref Armagan*

Support for Activities of daily Living

Impaired Visual acuity can affect various aspects of life particularly impacting on the routines of daily living. Steffie Schnitzler from Essen in Germany gives us important advice, on how to solve many of these difficulties.

Cooking

Injuries are always possible due to the problems in both food preparation and the cooking process. To reduce that risk as much as possible, keeping in mind the four following points may help.

- **Take your time! There are a lot of things which take more time with reduced vision**
- **Use a kitchen which is furnished for your requirements with optimal light**
- **Good organization and good planning**
- **High motivation for work in the kitchen is absolutely necessary**

To facilitate work in the kitchen, a variety of aids exists. For safe peeling of fruits and vegetables a *safe peeler* is suggested. In case you prefer to eat raw vegetables or thin slices for a soufflé, I suggest using a V-plane. For this aid you definitely should use finger protection! For chopping onions or similar work multiple manual or electric aids are available. My advice for these things: the chopper of Genius (QVC) is small, easy to handle and simple to clean.

Do you like eating noodles but are unsure when the water is boiling? Buy a *“Milkguide” (Figure 1)* made of porcelain. This small disc will be put into the pot. When the water is boiling, the disc starts to rattle due to the rising bubbles. When you then want to measure the correct boiling time for noodles you could use the timer “Al Dente”. This is a device you add to the water and after 7, 9 or 11 minutes different melodies are



Figure 1: “Milkguide”

played. Something similar exists under the name *“PiepEi”* for eggs: Detlef is the correct one for soft eggs, Schantall for medium cooked ones, and Hartmut for hard boiled eggs. Or you could use a big sized timer, depending on your remaining visual acuity. In addition alarm clocks in XXL are existing!

Now let’s go to work: Imagine we want to cook Spaghetti Bolognese for children. I will prepare everything in the following way: I chop the onions with the chopper in small cubes and place them in a container on the right side beside the stove. Garlic can be prepared in the same way as the onions, and will be placed in another small container just beside the onions. The tomatoes will be prepared. Olive oil will be measured in a measuring cup. For measuring fluids there exist *Measuring Cups* which measure liquid levels electronically. Spices for flavoring food can be measured with spoons, or judged by taking them in your hands. You should have a good system for storage so that the right spices are used (for example raised stick on labels or bright colors). After these preparations I take the minced meat out of the refrigerator. Now I can work from the left to the right side without hurry and without hurting myself. I keep this structured system in the refrigerator and also in the pantry. Items are kept in small baskets in specially marked places. In case your

vision is bad, but probably sufficient enough to chop the onions, but insufficient to see them later on a small tray, you need a *Working Tray with high Contrast*, e.g. in green. Contrasts are important at work, for preparing your table, but of course also for designing your rooms.

Now it is time to lay your table. Two points are important: work with contrasts and the *“Watch”*. Imagine your plate as a clock: then your drugs may be deposited always at 12 o’clock, the glass of water at 1 o’clock, and to the right of it is the coffee. To prevent that stinging insects disturb your drinks in the garden, various cups and glasses with covers leaving a small round for a straw, are available (*Figure 2*).



Figure 2: Cover for glasses

Washing clothes and using the iron

The simplest way to avoid the classic “Red T-shirt in white laundry” is to sort your laundry into various baskets, all for different colors. I have a small machine that recognizes colors, which I use for washing, ironing, removing things and shopping. In case you do not like playing Laundry-Memory with your socks, there are “*Sorters for Socks*” (Figure 3) available which you can use to fix both socks before cleaning.

After washing we all love the ironing: blouses and shirts should be ironed from the other side to avoid getting stuck on one of the pockets. For protection against burning your fingers you can use *iron foils*. Sorting clothes

also needs a system. A good one is to sort the clothes into ‘outfits’ using the color detector as above. For removing the ironed laundry various aids exist, like coat hangers, which you can hang above each other. So you can combine the fitting sets of clothes. The normal sorting of “skirts to skirts, trousers to trousers” is not really recommendable. How do I find the trouser I am looking for? There is the possibility to find your orientation with marking buttons, or to study the differences of your clothes in detail. In case that multiple trousers, blouses and skirts can be combined, I put these sets side by side, separating them by a piece of cardboard. Often also the adequate decoration (Jewels?) or a fitting shawl is added to this set. Because I can not distinguish colors anymore I use a *small machine that recognizes colors*, which I use for washing, ironing, removing things and shopping. Using this small device, I can take care for the outfit of my brothers and sisters without any problems, and for my two year old sister I was able to put together her clothes. They consisted of body for the baby, T-shirt, trouser, sweater and socks. Everything was put together into the non folded sweater and then the sweater got folded together.



Figure 3: “Sorters for Socks”

Shopping

In case of buying new clothes, take a friend or a family member with you who knows you and knows which clothes you like and how they fit together. Also for questions around the best make-up you should have friends with you. Every 4 weeks I get my eyelashes colored, that is cheaper and safer than new waterproof mascara. If you don't have a friend helping you, you should visit small shops where the service is mostly more personal.

Drugs

If you take drugs regularly, and you can not take them safely then it is important to use *“Drug Planners”* where drugs can be measured out and marked weeks in advance. Family members or friends could do this. The planners are available in Resource Centres or at the pharmacy. For more general drugs like pain killers, suppositories against fever, to name only two, everyone has to develop his or her own system. In my cupboard I have a reliable system: I keep my aspirin in the top left and on the right the tablets for the children. For measuring fever there exist *“Speaking Thermometers”*.

Money

In case you can not separate coins and notes sufficiently, there are aids available. For coins there exist boxes, in

which each coin has its own compartment. These *“Coinboxes”* (Figure 4) are available from special distributors (names see at the end of this article). I sort out at home the notes using the *“Cashtest”* machine (Figure 5). This is a template, which measures the length of the notes.



Figure 4: Coinbox “AMICO” (source: Marland)



Figure 5: “Cashtest” (source: Marland)

Stitching

To avoid mixing up my towels and flannels with the ones from my family, I have arranged **Buttons** on my things (*Figure 5*). For threading yarn into a needle there exists a “**Threading aid**”, which looks like a wire loop, additionally also a device called the “**Fairy Needle**”. This looks like a small factory. The needle will be put head-down into the chimney, behind the needle the yarn will be put on the path and a button has to be pressed. A small pin pushes the yarn through the eye of the needle. The yarn will be clicked into a “**Patent Needle**” (*Figure 6*). In case you like knitting but you are not perfect in remembering the pattern, one can use a spoken cassette, which you can hear while knitting.



Figure 5: Flannel, button attached

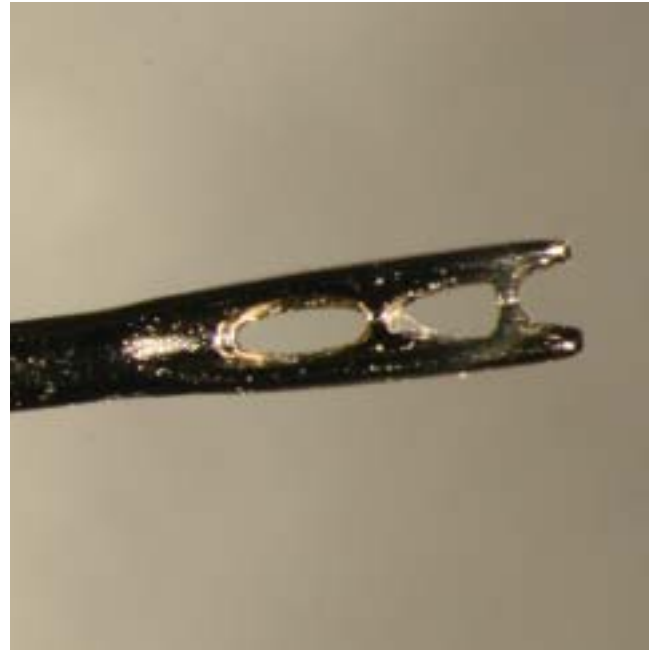


Figure 6: “Patent Needle”

Shopping List for the Supermarket

Dictating machines and cassette-recording machines are also very helpful to solve your daily problems. You can record your shopping list, dates, addresses, but also receipts. Using a dictating machine in the supermarket may need some overcoming in the beginning, but most people are more interested in themselves. And the two people who may have asked you finally, may admire you for shopping alone. You may also consider ear phones.

Probably the most important tip at the end

Be confident about your reduced visual acuity and easy going with others. Often

people are afraid of doing something wrong. Meeting people with an open mind, most people are very helpful. Often your own hindrances make it more difficult asking other people, especially when you previously did everything by yourself. I always was “Mother of the Company”, was on duty for everything and for everybody. I still do this, as much as I can, under the given circumstances. Whenever I need some help then I ask: customers in the supermarket, the bus driver, the neighbor, friends, family members, and of course my doctor. Only people who ask can have answers; those who do not ask, your face may not show that you need help. This applies also for the visit at your doctor. When you do not complain that you see the price tag only when the tag is on the level of your eyes during

shopping, he or she will not get the idea to order you a monocular, or to send you to the next low-vision clinic or to a school for visually impaired people. Those who do not dare will be restricted. I have learned that asking questions may not be easy, but it pays. Especially when you travel you should ask a lot. A buffet looks nice, but with a visual impairment you need a good translator. At the hotel reception you should ask that the room maid should leave the order of your room as you arranged it for yourself. Than you do not run into trouble at night cleaning your teeth with shampoo or make-up. A simple but good aid for this is a toilet bag with multiple compartments (e.g. Jack Wolf Skin) you can hang up. Such toilet bags are also very good when you are hospitalized.

The following internet addresses may help you to obtain the described aids and may provide you with additional help:

Aids for visual handicapped people – www.vzfb.de

Marland – Mail-order business for visual handicapped people – info@marland.de

Producer of: Detlef, Schantal, Hermann (boiled eggs) – info@brainstream.de

In the UK

Royal National Institute for the Blind Online Shop

Link to Kitchen Aids and utensils: can be viewed for ideas or bought from:

From there you can explore the shop for all sorts of aids for daily living.

Local resource centres are available to visit to see these items.

<http://onlineshop.rnib.org.uk/browse.asp?n=11&c=45&sc=114&it=1&l=3>

Low Vision and Uveitis: Patient Reports

Patient Report from UK

A UIG member shares her experiences of low vision aids.

I first came across visual aids when I was sent to a low vision clinic by the eye department at the hospital. The first items I used were hand-held magnifiers with lights and I still use a stronger version of these years later. I have a larger one for home and a small one to slip into my handbag which I find very useful in shops to read prices etc. A few years ago, through the disabilities officer at the local employment centre (job centre), I was given a CCTV computer, a 22inch screen for the computer and magnification software to use at work, along with training. These were the property of my employer but on leaving work several years later, I was allowed to take the CCTV computer and the software package away with me. This is part of a scheme called 'Access to Work' run by Jobcentreplus, a national government agency. It gives a grant to an employer to buy equipment needed to allow an employee to retain their job and adapt their workplace.

This equipment is 10 years old now, but fortunately, it has been replaced when I started a degree course with the Open University (OU). The OU offers university courses to degree level for students who can work from home and can be taken over a flexible time. They have an excellent support structure for students with visual impairments providing course material in all formats etc. A grant is offered to disabled students after an assessment of needs. It is a government initiative and is not related to income at all, only physical needs are accessed.

I would not like to manage without a CCTV computer to read my mail etc. I also find it useful for tasks other than reading, like cutting my nails and threading a needle. It does take practise but is worth the effort.

My local sight related charity has a resources centre so it is possible to view and try out equipment before purchases or even just browse to see what is available.

Jill Brocklebank

Two Patient Reports from Germany

A Patient Report from Germany No. 1 Good Expectations despite progressive visual Loss?

Today this statement is no longer a contradiction for me. But getting to this point was a long process which involved some luck.

Until 1990 terms like “visual acuity”, “angiography”, “cataract” and “vitrectomy” had no meaning to me. In that time I only kept an “eye” on my business goals which were more familiar to me. I could concentrate on this because my wife stayed at home after the birth of our first son in 1979 and looked after the household.

In December 1990 I went to see an ophthalmologist because of a sudden onset of blurring vision in my left eye. I was immediately referred to an eye clinic. A retinal vasculitis was diagnosed and treatment started with oral steroids. Since then several surgeries and steroid therapies were necessary.

In February 2004 I had a central vein occlusion in the right eye which had no visual problems until this time. Visual acuity raised again to 0.9 in this eye during treatment. Since this vein occlusion I take “blood-dilution” tablets. Neither the specialists in the eye clinic nor several ophthalmologists whom I

consulted were able to tell me the diagnosis, the reason or the prognosis of the disease.

According to the guidelines of the occupational medicine it was necessary for my job to have at least 0.8 vision in both eyes. As a precaution I changed my job in the company in 1995. I was able to practise the new job for several years with my visual impairment. Furthermore I gained additional qualifications in personal merchant from 1994 until 1995, besides my regular job. This gave me more occupational possibilities apart from my qualification as an engineer. The continuous “bit by bit” worsening of my visual acuity caused more and more stress in my business life. In the beginning I was able to compensate this stress with sports but the increasing stress and the fear for the future provoked sleeplessness, isolation from my family and in my social life. I even reduced all recreation activities and interests.

In April 2001 I was no longer allowed to drive a car because of the progressive visual loss. Additional to the eye disease I started to suffer from tinnitus and hypertension. With the help of my family I started psychotherapy. In 2002 I went to a health resort for treatment. At this time my visual acuity was 0.2 and 0.25 and the diagnosis was toxoplasmic retinochoroiditis or recurrent uveitis of unknown origin (an

autoimmune process).

With the help of my family, colleagues and friends and the psychotherapy I was able to gain back my activities and my normal life. I made an arrangement with my employer to assess my visual impairment for my job and my office was equipped with low vision aids. In July 2003 I consulted another eye clinic. They were able to diagnose the reason for my disease and a more effective therapy seemed to be possible. Also the negative development in my business gave me support: I was retired in 2005 using the legal process to assess and help employees before they get dismissal. Since 2003 the immunosuppressive therapy was varied many times. At the moment I take 2 immunosuppressive agents, which are very well tolerated, and a mild dosage of steroids. The uveitis is stable.

Despite my visual impairment I am able to move and walk independently in a known environment. This is possible due to an intact visual field beyond the central deficits of 30°. This makes many sighted people uncomfortable because they expect people with low vision with thick glasses or white stick to be insecure or unsteady. By adapting my ability to my potential and with the help of my family and friends I am able to have an active life and a good life quality

MDL

A Patient report from Germany No. 2

It started with great concern as often happens when you are older than 50 years and vision reduces. In November 2003 it was impossible to get an appointment for an eye doctor because of structural changes in health politics regarding financial support for glasses. So I went to an optician and got varifocals. The optician was fair and mentioned that it may take some time to get used to these new glasses. In January my vision had not improved and I went to see an ophthalmologist. She referred me to an eye clinic and the eye clinic directly to a uveitis centre.

Me and my husband, we were very concerned: What kind of disease is uveitis when only a specialist can help? With a lot of expectations we drove to the centre. And I had success, the therapy with CellCept tablets worked well and my visual acuity rose to 0.8. I felt to be "The Greatest", when I left the examination room. I already had detected that my vision had improved but the doctor gave me the confirmation. Before each examination I am always afraid of the measurement of the "percentage of visual acuity". My visual acuity was not stable, it started to decrease. At the moment it has stabilised on a low level, but I am happy when it stays like this.

How do I live with this situation?**Job**

In my office I installed magnifying software and I work with magnifying aids so that I am able to read and write in big letters. During work I have to switch between two glasses: a bifocal magnifying glass for reading, and a different one for writing. If the fax machine reports an error I nearly have to lay the nose on the display to be able to read it. Big problems to differentiate are round numbers like: 3, 6, 8 and 9.

Private life

It is a long time ago since I was crazy about reading. And I am not doing any embroidery any more. I stopped driving a car, biking or skiing. Not being allowed driving a car any longer was the hardest thing for me. You lose your independence. When I am not at home I have to know where the stairway is because I am afraid of using escalators in the downward direction (deep and fast). Or I have to ask for help, which confuses other people as I look quite normal. While watching television I have problems reading the subtitles in shows like "Who becomes a millionaire". Either with or without glasses I am unable to read the answers. I also changed my behaviour in doing my household: cleaning and ironing are done in a different way. I reduce my work and agree to be satisfied with less.

My internal feelings

I have asked myself so often: Why is it me, suffering from this disease? Why is it not possible to cure the vasculitis? I always took my tablets regularly, even the steroid tablets. Now I have to deal with diabetes mellitus. I even asked myself if this disease has been induced by psychological reasons: not wanting to see everything (while under personal stress). Is the vasculitis like a defending shield?

My visual acuity at the moment

My vision is stable at the moment. My gleam of hope is my retirement in autumn. I hope it will get better when there is no more stress for my eyes due to monitor reading.

Michèle Reichel**A patient report from France**

I am a school teacher of french literature, on extended sick leave for two years. This is my story, as a patient suffering from uveitis, describing its present course, treatments, different side effects, changing vision, from a personal viewpoint. Uveitis can have very different histories for different people, making it difficult to understand for outsiders.

My uveitis officially entered my life in 1994, with worrying terms like chorio-retinopathy and macular edema, delivered by the ophthalmologist after an angiogram. Without realising it, at that time, I began a new lifestyle, punctuated by restrictions, such as “no salt and sugar” in my diet. The path was slow, painstaking, and frustrating, until I went to the specialized service of a large hospital, in Paris. In May 1994, my very impaired vision required hospitalization, the first in a long series of stays in hospital. In the same period, we discovered I was pregnant: I was the first pregnant woman suffering uveitis in the ophthalmology service. My daughter, was born in 1996 without major problems, was thanks to the close coordination between ophthalmology and obstetric and internal medicine. However, I had a new recurrence toward the end of my pregnancy and I knew then that I must leave my baby after her/his birth and return to the hospital!

My life could be summarised by cycles of stabilisation, treatment of recurrences of inflammation, and waiting. Like many other patients, at each recurrence, I tried successive new treatments, often associated with corticotherapy: colchicine, Interferon-alpha, Methotrexate, Cell-cept®, Imuran®, antibiotics, Endoxan®, Humira®, Remicade® and recently a new molecule, the LX 211. The patients know very well the side effects of

these treatments, even if they feel these side effects in varying degrees. This with hindsight, I think the more painful are the radical changes that cause a severe uveitis, recurrent and bilateral. It is a shock wave that gradually alters family and professional life, and which modifies our relationship with the others and with time.

Many questions arise:

- How and when to travel with the possible recurrence?
- How do I keep the medications cold?
- How to travel and follow the restrictive diet during corticotherapy?
- How to cope with appointments, outings or holidays when the inflammation or fatigue appears again?
- How to cope with the daily difficulties of life?

During recent years, my vision has deteriorated considerably, so I was forced to “face up” to my problem, to reduce my suffering and try to do something about it. Getting around in “unknown territory” became uncertain, even dangerous and things around me became a source of problems and anxiety. I then went to a Rehabilitation centre specialised in Low Vision. After an evaluation by the team, they were able to plan how to help me by making the most of the vision that I had left. Thanks to these professionals, doctor, orthoptist, occupational therapist, psychologist and white cane instructor.

They help me to accept my visual handicap.

To have low vision can be like having the ‘Sword of Damocles’ hanging over your head, sometimes dwelling on days of probable blindness.

It is also to suffer to lack understanding from “normal” persons who can’t understand the visual problems linked with uveitis. To be partially sighted but not

blind, always between normal and handicapped situation, do not help to found equilibrium and identity.

Fortunately, doctors and patients’ associations help us to keep hope and to exchange our experience with low vision.

Jeanne Herauld

Patient Groups & Information

Uveitis Information Group

A patient led information and support group.

■ Activities

- Provision of information and support by letter, phone and email.
- Public meetings around the UK.
- Web site

■ To Contact:

POST: UIG, South House, Sweening. Vidlin, Shetland Isles, ZE2 9QE

EMAIL: info@uveitis.net

WEBSITE: www.uveitis.net



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¹ Pearce I; Dietary Supplements in AMD: RCO Focus, Issue 30, 2004

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Physicians and Uveitis

News from the Scientific World

The Uveitis Awards from the German Uveitis Patients Interest Group (**DUAG**) 2006 and 2007



Since 2003 the **DUAG** has supported uveitis research by donating awards to clinical and experimental uveitis research. One of the main goals within the constitution of the **DUAG** is to achieve “support of scientific research”. The award winning papers are regularly presented in form of short summaries in the journal *uveitis*. Because this journal is published now only once a year, this edition will present the awards of 2006 and 2007.

In September 2006 the awards were presented during the congress of the German Ophthalmological Society (**DOG**) in Berlin, and in 2007 during the congress of the **International Ocular Inflammation Society (IOIS)** in Paris. **Prof. Manfred Zierhut**, the President of the **DUAG**, describes the process to select the winners and the topics of the winning papers. As in the previous years **Bausch & Lomb Co.**, Rochester, USA, sponsored the awards, together with **Mr. Theisen** from Koblenz in Germany. We would like to thank the sponsors very much for their support!

Physicians and Uveitis

How the Winners were selected

As in the previous year there were two award categories, in the field of experimental and clinical uveitis research. A team of 6 experts had to choose the best 3 publications in each field, published in the scientific literature of the year 2006 and 2007. "Scientific Literature" relates to journals where articles are peer reviewed (means likely to be important and new). This secures a high level of quality in itself. The money award goes to the first author while the document of honour goes to the whole group.

In the first round, each expert had been asked to nominate what he or she thought were the best 4 articles. In the final round each expert had to give points to four of these nominated papers (5, 10, 15 and 20).

What was the Content of the winning Articles?

Until today the mechanisms leading to uveitis are not well known. Most of the **experimental uveitis** work today is currently undertaken in animal experiments. There are models of uveitis in mice and rats which are very important since they can mimic human uveitis.

There is increasing interest in the role of bacteria and viruses in the induction of uveitis. Zhang and co-workers analysed

the process of the retinal infection and propagation of cytomegalovirus, a very important problem in AIDS patients. Su and co-workers studied the mechanisms that are important for the expression of receptor-molecules in bacterial infection (so called "Toll-like receptors"). Terrada and co-workers established an animal model, which is particularly relevant to the analysis of new antigens leading to uveitis. Grajewski and co-workers analysed a subset of T-lymphocytes known as "T-regulatory cells" that seem to control start and end of each uveitis episode and are distinguished by their surface receptors from other immune cells. Tumor-necrosis-factor alpha ($TNF\alpha$) represents an important mediator during the inflammatory reaction, as Calder and co-workers were able to demonstrate. Using electrotransfer of plasmids Bloquel and co-workers were able to block $TNF\alpha$ by antibodies produced in the eye.

The articles of the **clinical uveitis** awards include reports about two well-described uveitic disorders. Damico and co-workers studied the Vogt-Koyanagi-Harada syndrome. They found that special structures of pigmented cells (melanocytes) are the target of an immune response leading to uveitis. Thorne and co-workers of the American AIDS-Research-Group were able to show that the HAART-therapy (drugs that kills HIV) used in most AIDS patients is very

Physicians and Uveitis

effective in preventing cytomegalovirus-retinitis, resulting in a better prognosis for visual acuity compared to the pre-HAART-therapy era. Macular edema represents the most frequent complication of uveitis with implications for visual acuity as shown by Lardenoye and co-workers. Finally new therapeutic ideas were awarded. Jaffe and co-workers had shown in two studies (both winning an award) that a fluocinolone-device implanted through the sclera into the vitreous, releasing a small amount of corticosteroids each day for about 3 years, was able to significantly reduce the amount of uveitis recurrences. As mentioned before the $TNF\alpha$ molecule can be blocked successfully with antibodies, as investigated by Suhler and co-workers.

publications offer important new contributions to the therapy of uveitis or improve our knowledge regarding the mechanisms playing key roles in experimental uveitis. They all, therefore probably provide ideas for new therapeutic developments. Making new scientific results easily and quickly available to ophthalmologists, and also to health insurances, is a major goal for patient interest groups in all countries. This will ensure a modern and more successful approach to diagnosis and therapy for uveitis patients.

Why do we need Uveitis Awards?

The **DUAG** awards are still the only awards for uveitis donated yearly. This is even more special because they are donated in the name of an ocular disease patient interest group. We plan to establish the awards as a qualification criterion in the coming years so as to help the winners in their careers giving them a better chance of obtaining research grants and thereby expanding research into uveitis.

As in the previous years, the Committee and the **DUAG** agreed that all six awarded



The Uveitis Award Winners of 2006



The Uveitis Award Winners 2006 – from the left to the right side:

*Eric B. Suhler (Portland, USA), Christoph Keßler (Bausch & Lomb, Sponsor),
Claudia J. Calder (Bristol, UK), Manfred Zierhut (DUAG, Member of the Award
Committee, Germany), Shao Bo Su (Bethesda, USA), Francisco M. Damico
(Sao Paulo, Brasil), Ming Zhang (Augusta, USA)*

Physicians and Uveitis

The Uveitis Award Winners of 2007



The Uveitis Award Winners 2007 – from the left to the right side:

Manfred Zierhut (DUAG, Member of the Award Committee, Germany), Jennifer Thorne (Baltimore, USA), Céline Terrada (Paris, France), Sylvain Fisson, (Paris, France), Bahram Bodaghi (French Patient Interest Group, Member of the Award Committee), Charlotte Lardenoye, Aniki Rothova (Utrecht, The Netherlands), Rafael S. Grajewski (Würzburg, Germany), Francine Behar-Cohen (Paris, France), Yvonne de Kozak (Member of the Award Committee)

The Experimental Uveitis Awards 2006

1st award

**Claudia Jane Calder, Lindsay Boyd Nicholson,
Andrew David Dick**

A selective Role for the TNF p55 Receptor in autocrine Signalling following IFN-gamma Stimulation in Experimental Autoimmune Uveoretinitis

Published in: Journal of Immunology 2005;175:6286-6293

In uveitis, inflammation occurs without infection and largely affects the layers of the back of the eye including the retina. Our uveitis work at the University of Bristol focuses on cells of the immune system, particularly the role of the macrophage a cell which causes most of the damage to the eye's retina.

As inflammation occurs, immune cells enter the eye (T-cells and macrophages) and release potent chemicals and proteins called cytokines that generate and promote further inflammation. Tumour-Necrosis-Factor (TNF) is such a cytokine, released during inflammation and activates macrophages to damage retinal tissue via their production of oxidising agents such as nitric oxide.

For TNF to work, it needs, like a lock and key, to link to its receptor on the surface of most immune cells. Our research has shown that in an experimental model of uveitis TNF and the presence of the TNF-receptor is critical for the start of the disease. In the absence of the TNF-receptor, macrophages within the eye are unable to respond and so no damage to the retina occurs. These findings have been translated into practice where successful treatment with anti-TNF agents helps to reduce the damage in uveitis.



*Fig.: 1st Experimental Award –
from the left to the right side:
Christoph Keßler (Bausch & Lomb, Sponsor),
Claudia J. Calder (Bristol, UK)*

2nd award

Shao Bo Su, Phyllis B. Silver, Rafael S. Grajewski, Rajeev K. Agarwal, Jun Tang, Chi-Chao Chan, Rachel R. Caspi

Essential Role of the MyD88 Pathway, but nonessential Roles of TLRs 2, 4 and 9, in the adjuvant Effect promoting Th1-mediated Autoimmunity

Published in: Journal of Immunology 2005;175:6303-6310

In the process of human uveitis the body generates cells, known as effector T-lymphocytes that can recognize retinal antigen in the eyes. These cells migrate into the eye and recruit other leukocytes, which destroy photoreceptors, resulting in impaired vision. Experimental autoimmune uveitis (EAU) is an animal model for the study of human autoimmune uveitis. Induction of EAU requires immunization of animals (usually mice or rats) with retinal proteins such as the interphotoreceptor retinoid binding protein (IRBP) emulsified in oil containing heat-killed *Mycobacterium tuberculosis* (MTB). This bacteria in oil mixture is known as Complete Freund's Adjuvant (CFA). The bacteria are perceived by the body as a "danger" signal, and stimulate production of the inflammatory effector T-lymphocytes also to the retinal protein that is mixed with the bacteria, resulting in uveitis.

The recognition of bacteria as "danger" depends on molecules on the surface of immune cells, known as Toll-like receptors (TLRs), which have become specialized during evolution to detect bacterial components. These receptors and the responses triggered by their activation constitute the first line of defense against many pathogens. Thus far, 11 TLRs have been identified and they are labeled from TLR1 to TLR11. The activated TLRs then signal through the adaptor molecule MyD88 to induce an immune response.

Because bacterial components must be mixed with IRBP to support EAU induction, we asked whether TLRs might play an important role in the induction of EAU. We studied the role of selected components of the MyD88 pathway in promoting EAU. Mice made deficient for MyD88, TLR2, TLR4 or TLR9 by genetic engineering were all immunized with the retinal antigen in CFA as if to induce uveitis.

Surprisingly, mice deficient for TLR2, TLR4 and TLR9 (all TLRs triggered by mycobacteria) were as susceptible to EAU as the original, genetically unaltered, mouse strain. However, MyD88 deficient mice were completely resistant to EAU, indicating MyD88 as a critical molecule for EAU induction. This suggested that

Experimental Awards 2006

molecules other than these TLRs that also signal through MyD88 must be involved.

It is known that cell surface receptors that bind endogenous inflammatory cytokines Interleukin-1 (IL-1) and IL-18 also signal through MyD88. We therefore examined the EAU induction in genetically engineered IL-1 receptor deficient mice and IL-18 deficient mice. The IL-1 receptor deficient mice, but not the IL-18 deficient mice, were resistant to EAU.

These data are compatible with the interpretation that TLR2, TLR4 and TLR9 signaling is not needed, or, more likely, redundant, as "danger" signals to induce EAU. In contrast, signaling through the IL-1 receptor plays a necessary role in EAU, and can by itself account for the lack of EAU development in MyD88 deficient mice.



*Fig.: 2nd Experimental Award –
from the left to the right side:
Volker Becker (DUAG, Germany),
Shao Bo Su (Bethesda, USA)*

3rd award

Ming Zhang, Hua Xin, Penny P. Roon, Sally S. Atherton

Infection of retinal Neurons during murine Cytomegalovirus Retinitis

Published in: Investigative Ophthalmology and Visual Science 2005;46:2047-2055

Cytomegalovirus (CMV) retinitis is the most common sight-threatening opportunistic infection observed in adult and pediatric patients who are immunosuppressed as a result of chemotherapy, malignancy, or the acquired immunodeficiency syndrome (AIDS). CMV chorioretinitis, the most frequent ocular abnormality in congenital CMV infection, is observed in approximately 15% of infants who have developed the disease. One difficulty studying the pathogenesis of CMV infections is that the members of cytomegalovirus are species restricted which means that human CMV (HCMV) will not replicate in the mouse, and conversely, murine cytomegalovirus (MCMV) will not replicate in the human. However, the many similarities between two viruses have made MCMV a useful tool in deciphering the mechanisms of CMV infections in human patients. A mouse model of MCMV retinitis with features resembling HCMV retinitis in human patients has been established and studied in our laboratory. In this model, inoculation of MCMV into immunosuppressed BALB/c mice via the supraciliary route results in necrotizing retinitis. The purposes of the studies reported in this paper were to identify which retinal cells are infected and to determine the routes by which MCMV spreads in the retina in our model of MCMV retinitis. Our results showed that the retinal pigment epithelial (RPE) cells were the initial site of MCMV infection in the retina. Virus then spread from the RPE and the photoreceptor layer to the inner retina through infected Müller cells and within the inner retina horizontally through infected horizontal cells. In the inner retina, horizontal and bipolar cells were the early (on or before day 7 after infection) targets of MCMV infection followed by glia cells (from day 10 after infection). Results from electron microscopy studies support the idea that MCMV infection leads to death of uninfected neuronal cells using natural cell death (apoptosis) which may contribute to the pathogenesis of MCMV retinitis.



Fig.: 3rd Experimental Award – from the left to the right side: Elke Dettmann (DUAG, Germany), Ming Zhang (Augusta, USA)

The Experimental Uveitis - Awards 2007

1st award

Rafael S. Grajewski, Phyllis B. Silver, Rajeev K. Agarwal, Shao-Bo Su, Chi-Chao Chan, Gregory I. Liou, Rachel R. Caspi

Endogenous IRBP can be dispensable for Generation of natural CD4+CD25+ regulatory T-cells that protect from IRBP-induced retinal Autoimmunity.

Published in: Journal of Experimental Medicine 2006;17:851-856

Experimental autoimmune uveitis (EAU) in the laboratory mouse is an animal model used to examine important aspects of human uveitis. EAU is induced by immunization with proteins isolated from the retina of the eye, such as the interphotoreceptor retinoid-binding protein (IRBP). The body recognizes proteins of the retina as foreign and directs an immunological response against the IRBP. Lymphocytes known as effector T-cells are the most important cells that orchestrate this response. Another subgroup of T-cells, known as regulatory T-cells (T-reg), is able to control the effector T-cells. We have shown in a previous study that such cells can prevent or inhibit uveitis from becoming chronic. The requirements for production and for activation of these protective cells (characterized by the surface structures CD4+CD25+) that can control uveitis, were examined and characterized in the present work. Here we wanted to examine whether development of T-reg-cells that recognize IRBP and can control uveitis induced by IRBP, must be present in the eye or anywhere in the body. Such a requirement had been demonstrated for several other tissue proteins.

We used mice in which the IRBP molecule was deleted from the entire body using genetic engineering (IRBP knock out) (KO) but which were otherwise genetically identical to the original strain (referred to as wild type) (WT). The assumption was that upon removal of T-regs the WT mice would develop stronger responses to IRBP, but mice without IRBP would not if they had no T-regs able to inhibit their responses.

Surprisingly, T-regs appeared to be functional whether the IRBP was naturally in the body or not, because removing all protective cells led to a stronger inflammatory reaction in both the mutant and the WT mouse strains. We then wondered whether the bacterial components, which must always be incorporated into the immunization mixture with IRBP (known as Complete Freund's Adjuvant) might be stimulating T-regs that do not recognize IRBP and would normally remain inactive. Indeed, when immunization was carried out without this bacterial component only the WT mice showed a reinforced inflammation directed against IRBP after T-reg removal.

From these experiments we concluded that indeed IRBP must exist in the body for the development of T-regs that recognize IRBP. However, EAU can be controlled by T-regs that recognize other proteins after they are activated by the bacterial components. We hypothesize that the bacterial components trigger T-regs into action independently of the specific proteins they recognize, by acting through specialized "danger" receptors present on all cells, including T-regs. When activated, T-regs are able to control the effector cells that recognize IRBP and cause uveitis even if the T-regs themselves do not recognize the IRBP protein.

Thus, the same bacterial components that are necessary to elicit the disease as part of the immunization mixture also help to control the disease by triggering regulatory T-cells. This ability of bacterial components to trigger both effector and regulatory T-cells could be involved in the connections between autoimmune diseases such as uveitis and (preceding) infections. The possibility to manipulate such antigen specific regulatory T-cells without influencing the whole immune system, and a transfer of such technologies to humans, is an important goal in uveitis research.



Fig.: 1st Experimental Award – from the left to the right side: Chantal Couderc (Bausch & Lomb, Sponsor), Rafael S. Grajewski (Würzburg, Germany)

2nd award

**Carole Bloquel, Riad Antoine Bejjani, Pascal Bigey,
Fethi Bedioui, Marc Doat, David BenEzra,
Daniel Scherman, Francine Behar-Cohen**

Plasmid Electrotransfer of Eye ciliary Muscle: Principles and therapeutic Efficacy using hTNF-alpha soluble Receptor in Uveitis.

Published in: The Federation of American Societies for Experimental Biology
2006;20:389-391

For eye diseases, systemic administration of drugs is problematic. Due to the existing ocular barriers, high drug concentrations are needed and the potential for secondary complications enhanced. To circumvent the need for systemic treatment and avoid secondary complications, ocular local therapy is ideal. Furthermore, in most chronic diseases, a constant and highly efficient drug level for an extended period of time is needed. Due to its relatively small size and its particular isolating characteristics, the eye is an ideal target for development of local therapeutic means. At the present, development of specific ocular drug delivery systems is a major research avenue in ophthalmology. Electrotransfer has attracted our interest and its potential local therapeutic application for ocular diseases, the focus of our studies. Electrotransfer is a most efficient non-viral delivery technique which can be used not only for gene transfer.

In the present study, we used the ciliary muscle as a reservoir for a long standing intraocular expression and secretion of therapeutic molecules. The ciliary muscle is located just below the sclera, and its prolongations reach the anterior retina. It is located at the crossroad between the anterior and posterior segment allowing for possible protein expression both into the aqueous humor and into the vitreous.

Using these methods, we attempted to specifically transfect ocular ciliary muscles of rat eyes. Plasmid encoding for either green fluorescent protein (GFP) or luciferase (Luc) have been used to trace and dose intraocular post transfection gene expression. The therapeutic potential of this technique was then evaluated in rats with endotoxin-induced-uveitis (EIU) using a plasmid with a gene encoding for human TNF- α soluble receptor I (hTNFR-Is).

Plasmid electrotransfer in the ciliary muscle allowed for the expression of reporter genes in the ciliary muscle fibers for at least 6 months. In the experimental rat model, high levels of hTNFR-Is in the aqueous humor along with significant

inhibition of clinical and histology scores of intraocular inflammation were observed. In the serum of these rats however, no detectable levels of hTNFR-Is were found, demonstrating the local aspect of protein delivery with this method. Plasmid electrotransfer to the ciliary muscle, as performed in this study, did not induce any ocular pathology or structural damage.

These results show that the ciliary muscle can be used for plasmid electrotransfer with high yield of therapeutic proteins within the eye. When therapeutically indicated, local production of anti-TNF proteins through ciliary muscle electrotransfer can be a feasible alternative to systemic anti-TNF therapy.

Electrotransfection of plasmids into muscles and the possibility to use the muscle cell protein synthesis machinery for the long standing production of proteins opens additional interesting possibilities.



Fig.: 2nd Experimental Award – from the left to the right side: Francine Behar-Cohen (Paris, France), Aniki Rothova (Dutch Patient Interest Group, Utrecht, The Netherlands)

3rd award

Céline Terrada, Sylvain Fisson, Yvonne de Kozak,
Mohammed Kaddouri, Phuc LeHoang, David Klatzmann,
Benoît L. Saloman, Bahram Bodaghi

Regulatory T-cells control Uveoretinitis induced by pathogenic Th1 Cells reacting to a specific retinal Neoantigen

Published in: Journal of Immunology 2006;176:7171-7179

In this study, we described a new and reproducible model of uveitis. Unlike classical models of autoimmune experimental uveitis, uveitis was obtained in BALB/c mice one month only after intraocular injection of a viral vector inducing the expression of hemagglutinin antigen (HA) in the retina. Therefore, no genetic background was necessary to induce the disease. Mice were injected in the tail vein with activated lymphocytes specific for HA. Importantly, our model adds the unique possibility to follow the pathogenic T-cell behaviour and migration at a level not possible in previous models. The HA-neoantigen expressed in the retina, attracts and activates HA-specific effector T-lymphocytes that initiate retinal lesions and clinical signs of uveitis. Intraocular inflammation was clinically and histologically detected in all animals.



*Fig.: 3rd Experimental Award –
from the left to the right side:
Stefan Thurau (DUAG, Munich, Germany),
Céline Terrada (Paris, France)*

In our model, T-lymphocytes could be traced using markers, which provide a unique tool for better understanding the pathophysiology of uveitis, such as migration, specificity, activation and effector functions of pathogenic cells. After activation in peripheral draining lymph nodes, HA-specific T-cells crossed the blood-ocular barrier of both eyes, due to its permeability to activated T-cells. Therefore, HA-T-cells were detected only in the eye expressing HA, and not in the eye expressing a control antigen.

The model helps to shed light on the mechanisms driving human disease. The following scenario for the pathophysiology of HA-uveitis can be proposed: T-cells specific for a retinal antigen are initially activated in peripheral lymphoid tissues. Then, they migrate into the eye and are further activated by local antigen presenting cells processing the cognate antigen to obtain the disease. Interestingly, specific HA-specific regulatory T-cells were able to dramatically decrease intraocular inflammation, when administered systemically or intravitreally.

Supporting a commonality of mechanisms between experimental and human disease, successful immunomodulation of the model using regulatory T-cells could be predictive of clinical success.

The Clinical Uveitis - Awards 2006

1st award

Glenn J. Jaffe, Rex M. McCallum, Brenda Branchaud,
Cindy Skalak, Zuhail Butuner, Paul Ashton

Long-term Follow-up Results of a Pilot Trial of a Fluocinolone Acetonide Implant to treat posterior Uveitis

Published in: Ophthalmology 2005;112:1192-1198

To overcome the limitations of currently available drug delivery routes, delivery systems for the sustained release of medication within the posterior segment have been developed. These systems offer a promising approach to the treatment of ocular disease in cases where systemic drug administration may be associated with unacceptable toxicity and where repeated intravitreal injection carries unacceptable risk. A non-biodegradable fluocinolone acetonide intravitreal implant has been developed. In pharmacokinetic studies drug delivery was linear for approximately 1000 days.

In November 2000, we reported results of the first human study to use a fluocinolone acetonide implant to treat seven eyes of five patients with severe posterior uveitis. In that study, 10 months on average following device implantation, visual acuity was stabilized or improved, and inflammation was controlled in all eyes. In the present study, we expand on the initial investigation and report the results of a long-term prospective study of the implant to treat patients with severe uveitis.

Thirty-six eyes of 32 patients with a history of recurrent non-infectious posterior uveitis were randomly assigned to receive either a 0.59 mg or 2.1 mg fluocinolone acetonide intravitreal implant. Patients were followed every 4 to 6 weeks for the first 3 months and then every 3 months thereafter. Pre-operative and post-operative ocular inflammation, visual acuity, anti-inflammatory medication use and safety were the outcomes used to assess the effect of the implant.

On average, patients were followed for 683 ± 461 days (ranging from 204 to 1817 days). At baseline, the average visual acuity for the device-implanted eyes was 20/250, which improved significantly to 20/125 at 30 months. Inflammation was effectively controlled over the follow-up period. The average number of recurrences in the 12 months prior to implantation was 2.5 episodes per eye. None of these eyes experienced a recurrence for the first 2 years post-implantation. There was a reduction in systemic and local therapy use in the device-implanted eyes; of the patients who remained on systemic medication

post-implantation, dosage was reduced in 68%. Periorbital steroid injections decreased from an average of 2.2 injections per eye per year to 0.07 injections per eye per year. The most common adverse event was a rise in intraocular pressure. At baseline 16.7% of eyes used pressure-lowering agents compared to 47.6% over the follow-up period. Filtering procedures to lower intraocular pressure were performed in 7 eyes (19.4%). Four of the eight phakic eyes, each of which had some level of cataract at device implantation, subsequently underwent cataract extraction. There were no device explantations (removed surgically) or patients lost to follow up during the investigation.

The fluocinolone acetonide intravitreal implant effectively controlled intraocular inflammation in the studied population. Elevated intraocular pressure and cataracts that occurred in fluocinolone device-implanted eyes were managed by standard means. The fluocinolone acetonide sustained drug delivery implant appears to be promising in patients with posterior uveitis who do not respond to, or are intolerant to, conventional treatment.

2nd award

**Eric B. Suhler, Justin R. Smith, Michael S. Wertheim,
Andreas K. Lauer, Daryl E. Kurz, Terri D. Pickard,
James T. Rosenbaum**

A prospective Trial of Infliximab Therapy for refractory Uveitis: Preliminary Safety and Efficacy Outcomes

Published in: Archives of Ophthalmology 2005;123:1000-1001

In a prospective clinical study, we treated 31 patients with sight-threatening, non-infectious uveitis that had not responded to more conventional therapies with infliximab (Remicade™). Infliximab is a member of a class of drugs known as tumor necrosis factor (TNF) blockers. TNF is a molecule secreted by inflammatory cells which plays an important role in initiating and maintaining inflammation in normal and disease states and its block had been demonstrated to be effective in diseases such as rheumatoid arthritis and ankylosing spondylitis.

Refractory uveitis was defined as disease which was either non-responsive to therapy with corticosteroids plus at least one “standard” immuno-suppressive, or cases in which therapy could not be tolerated due to toxicity. The study period was originally 50 weeks, but was extended to two years. Patients received infliximab infusions at enrollment (week 0), and at weeks 2 and 6. Defined time points to decide if the study drug was effective were at 10, 50, and 106 weeks after starting therapy. Effectiveness was judged using visual acuity, control of inflammation, reduction of corticosteroids or other immunosuppressives by 50% or greater and reduction of inflammatory signs (measured by fluorescein angiography or ocular coherence tomography).

At 10 weeks, 24 of 31 patients were judged as “successes” and were allowed to continue in the study. Data not presented in the original paper (pending publication now) that were presented in Berlin to the DUAG in October 2006 were that approximately 60% of patients that were successes at week 10 continued to receive the drug at week 50, and of these, another 60% were able to continue to two years. The principal reason for discontinuation of infliximab after initial success was due to side effects, which included drug-related lupus (all 3 remitted with discontinuation of infliximab), thromboembolic side effects (2, both in higher frequency than had been reported previously), as well as two infusion reactions, one case of congestive heart failure, one significant infection, and one malignancy. We have to point out that causation of the side effects in many cases was not clearly related to infliximab.

The study shows that infliximab is a very effective drug in the treatment of refractory cases of non-infectious uveitis, but remind all practitioners that infliximab and other biologic medications are potent medications, and that vigilance is required for the development of known and unknown toxicity in all patients.



*Fig.: 2nd Clinical Award – from the left to the right side:
Hans-Jürgen Werndt (Bausch & Lomb, Sponsor),
Eric B. Suhler (Portland, USA)*

3rd award

**Francisco Max Damico, Edecio Cunha-Neto,
Anna Carla Goldberg, Leo Kei Iwai, Maria Lucia Marin,
Jürgen Hammer, Jorge Kalil, and Joyce Hisae Yamamoto**

T-Cell Recognition and Cytokine Profile induced by Melanocyte Epitopes in Patients with HLA-DRB1*0405-positive and -negative Vogt-Koyanagi- Harada Uveitis

Published in: Investigative Ophthalmology and Visual Science 2005;
46:2465-2471

Vogt-Koyanagi-Harada disease (VKH) is an autoimmune disorder principally affecting pigmented tissues in the ocular, auditory, skin, and central nervous systems. VKH affects mainly pigmented races and is a major cause of uveitis in Japan and in Brazil. It occurs more commonly in genetically susceptible individuals. HLA-DRB1*0405 is the main susceptibility allele.

VKH may be associated with headache, neck stiffness (meningism), hearing loss, and ringing in the ears (tinnitus). Chronic findings consist of loss of skin pigment (vitiligo), and areas of hair loss and whitening. Systemic corticosteroids are the first line therapy, and nearly two-thirds of the patients retain good visual acuity with prompt diagnosis and aggressive therapy. However, a significant number of patients will have a poor outcome.

The exact pathological mechanism for VKH has not been completely elucidated. Evidence suggests that it is a cell-mediated immune disorder directed against self-antigens found predominantly in melanocytes (cells which produce the brown melanin pigment). However, neither the trigger of the autoimmune response nor the exact pathogenesis is completely understood. Since the Brazilian population is an ethnically mixed population in which a significant number of individuals do not carry the susceptibility allele, our group studied the differences in the immune responses between patients carrying the HLA susceptibility allele and those carrying other alleles.

In this study, we first showed that VKH patients' lymphocytes can recognize four different melanocyte proteins (tyrosinase, tyrosinase-related protein 1 and 2, and Pmel-17), suggesting that these proteins are the target of the autoimmune response. Then, we synthesized 28 peptides (small protein fragments) derived from those melanocyte proteins which were predicted to be recognized by lymphocytes with the susceptibility allele. When we put lymphocytes from

patients and from control subjects (with the susceptibility allele or not) together with the peptides, we found that lymphocytes from patients with VKH recognized more melanocyte-derived peptides than control subjects and at lower concentrations.

These findings reinforce the importance of this HLA-type in susceptibility to the development of VKH disease and the importance of melanocytes as targets in this disease. In addition, 3 peptides were exclusively recognized by patients with HLA-DRB1*0405, suggesting that after the first recognition of a melanocyte protein, there is a cross-reactivity against other melanocytic proteins and a spreading of the immune response.

In summary, our study shed some light to the pathogenesis of VKH disease, by showing the importance of melanocytic proteins and the susceptibility allele HLA-DRB1*0405. These findings may be helpful for the development of new treatments for VKH disease.



Fig.: 3rd Clinical Award – from the left to the right side: Manfred Zierhut (DUAG, Tübingen, Germany), Francisco M. Damico (Sao Paulo, Brasil)

The Clinical Uveitis Awards 2007

1st award

Jennifer E. Thorne, Douglas A. Jabs, John H. Kempen, Janet T. Holbrook, Charles Nichols, Curtis L Meinert; for the Studies of Ocular Complications of AIDS Research Group

Incidence of and Risk Factors for visual Acuity Loss among Patients with AIDS and Cytomegalovirus Retinitis in the Era of Highly Active Antiretroviral Therapy

Published in: Ophthalmology 2006;113:1432-1440

Retinitis induced by cytomegalovirus (CMV, belongs to the herpes group of viruses) is a common complication among patients with the Acquired Immunodeficiency Syndrome (AIDS). In 1996 new drugs, commonly referred to as Highly Active Antiretroviral Therapy (HAART), became available for widespread use in the treatment of AIDS. These drugs allowed for suppression of the Human Immunodeficiency Virus (HIV) and recovery of the immune system, which has allowed patients with AIDS to live healthier lives. Prior to the availability of HAART, CMV retinitis occurred in approximately 30% of patients with AIDS during their lifetime. CMV retinitis causes destruction of the retina which without

treatment will result in permanent blindness. Because treatment for CMV retinitis does not cure the disease, life-long treatment is required and recurrence of the eye infection with progression of retinal destruction was common prior to HAART.

Since the advent of HAART, the incidence of CMV retinitis has declined by 80% and the occurrence of progression of complications due to CMV retinitis such as retinal detachment has declined. Because of these changes in the clinical history of CMV retinitis, we sought to study the incidence of visual acuity loss due to CMV retinitis among



Fig.: 1st Clinical Award – from the left to the right side: Bahram Bodaghi (French Patient Interest Group, Member of the Award Committee, Paris), Jennifer Thorne (Baltimore, USA)

patients with AIDS and treated with HAART. We also assessed the risk factors and possible causes for any vision loss that we found.

There were 379 patients in our cohort (enrolled in the “Longitudinal Study of Ocular Complications in AIDS”) with CMV retinitis. Approximately 34% of patients had bilateral disease yielding 494 eyes with CMV retinitis for evaluation. Three-quarters of patients were taking HAART at the time of enrollment in our study. Overall, we found the rate of vision loss in our cohort to be approximately 9-fold less than that observed in the era prior to HAART. The rate of 20/50 or worse vision (visual impairment) was 0.10/per eye year and the rate of blindness (20/200 or worse) was 0.06/per eye year. Approximately half of the cohort had undergone recovery of their immune system due to taking HAART with subsequent rises in their lymphocyte levels. Immune recovery was associated with a 40% to 60% reduction in the rate of vision loss among our patients.

However, immune recovery may often lead to inflammation throughout the body as the immune system “wakes up” after the HIV virus load in the blood is suppressed. Within the eye this can lead to intraocular inflammation known as “Immune Recovery Uveitis” (IRU). IRU may cause ocular complications in the eye that also can affect vision. Indeed, the rate of vision loss among patients with immune recovery who also had IRU had higher rates of visual impairment (20/50 or worse vision) than did patients without IRU, but similar rates of blindness (20/200 or worse vision). We investigated the potential causes for vision loss in our patients and found that among patients whose immune system remained suppressed, the reasons for vision loss was due almost exclusively to the CMV retinitis either due to destruction of the central part of the vision known as the macula, or due to a retinal detachment caused by the CMV infection in the eye. However among patients who had immune recovery, IRU and complications of IRU, such as cataract or swelling in the back of the eye known as macular edema, accounted for one-half of the vision loss in these patients.

Our study found that visual acuity outcomes have improved in the area of HAART, with those patients with immune recovery and without IRU having the lowest risk for visual impairment and blindness. Although retinal destruction and retinal detachment due to CMV retinitis remain common causes of vision loss among patients CMV retinitis, IRU and its complications may also result in mostly mild to moderate vision loss.

2nd award

**Charlotte W.T.A. Lardenoye, Bram van Kooij,
Aniki Rothova.**

Impact of macular Edema on visual Acuity in Uveitis

Published in: *Ophthalmology* 2006;113:1446-1449

Macular edema is an accumulation of fluid in the central part of the retina, the area that we use to read, drive and to recognize faces. It may be caused by several ocular disorders such as uveitis, diabetic retinopathy, and other diseases affecting the retina. It may also develop following intraocular surgery and radiation therapy. So far, the impact of macular edema on the visual prognosis in uveitis and its specific forms was unknown.

In our study we investigated clinical data from 529 patients (842 eyes) with uveitis. The mean age of our patients was 46 years. Macular edema caused visual loss in 44% of patients between 18 and 65 years of age and formed therefore the most important factor determining visual loss in the working age group of the uveitis population. Macular edema in at least one eye was observed in 175 patients (33%), of whom 77 (44%) had a visual acuity which could be classified as visual impairment (less than 0.3). Macular edema was the cause of visual impairment in 42%.

Severe visual impairment was most commonly seen in panuveitis and was caused by macular edema in almost 60% of these eyes. In intermediate uveitis, a majority of patients developed some degree of macular edema, but only 28% of patients experienced severe visual impairment. Interestingly, the cause of the uveitis played a crucial role in the visual impact of macular edema. Macular edema which caused visual loss was seen mainly in birdshot chorioretinopathy, sarcoidosis, and acute retinal necrosis. Macular edema was seen less frequently in viral infections of the anterior segment and HLA-B27 associated uveitis.

Another interesting finding in our study was the observation that loss of visual acuity due to macular edema was associated with increasing age. Patients older than 50 years had a higher chance of developing macular edema and also to lose visual acuity as a consequence of this complication. Hypothetical explanations for this finding may include decreased function or degeneration of retinal cells during life, a process that may be enhanced by an intraocular inflammation.

In conclusion, we have confirmed that macular edema is a major complication causing visual decrease in uveitis and is especially severe among elderly patients and those with chronic disease. Our findings emphasize the need for early treatment of this uveitis complication



*Fig.: 2nd Clinical Award – from the left to the right side:
Claude Andrieux (President of the French Patient Interest Group),
Charlotte Lardenoye (Utrecht, The Netherlands)*

2nd award

**Glenn J. Jaffe, Daniel Martin, David Callanan,
P. Andrew Pearson, Brian Levy, Timothy Comstock,
(Fluocinolone Acetonide Uveitis Study Group)**

Fluocinolone Acetonide Implant (Retisert™) for non-infectious, posterior Uveitis: 34-week Results of a Multicenter randomized clinical Study

Published in: *Ophthalmology* 2006;113:1020-1027

We report the interim, 34-week results of a multicenter, masked, historically-controlled, dose-randomized pivotal trial conducted in the United States and Singapore designed to test the safety and efficacy of the fluocinolone acetonide (FA) sustained drug delivery system to treat severe posterior uveitis. This is a device that is surgically implanted inside the eye and releases steroid into the eye for up to 3 years.

A total of 278 patients with recurrent non-infectious posterior uveitis were randomly assigned to receive a 0.59 mg (110 patients) or 2.1 mg (168 patients) implant. After the implant was surgically inserted through the pars plana, patients were followed-up on day 2, week 1, and then every 4 to 6 weeks through 34 weeks. Systemic, periocular and topical therapy were reduced as allowed by the clinical response.

The FA implant reduced the rate of recurrences from 51.4% in the 34 weeks preceding implantation to 6.1% post-implantation in the study eyes. Comparatively, there was a significant increase in the recurrence rate in the fellow non-implanted eyes from 20.3% pre-implantation to 42.0% post-implantation. Visual acuity was stabilized or improved in 87% of implanted eyes and was generally associated with reductions in cystoid macular edema. The percentage of eyes that required systemic medications, periocular injections, and topical corticosteroids decreased from 52.9%, 63.0%, and 35.7%, respectively, pre-implantation to 12.1%, 2.2%, and 16.5%, respectively, post-implantation. At week 34, 51.1% of implanted eyes required ocular anti-hypertensive drops and 5.8% underwent glaucoma filtering surgery. Lens opacity scores increased by ≥ 2 grades in 19.8% of phakic implanted eyes and 9.9% required cataract surgery. There were no statistically significant differences in any of the parameters studied for the 0.59 mg implant, compared to the 2.1 mg implant.

From this study, we conclude that the fluocinolone acetonide implant significantly reduced uveitis recurrences, improved visual acuity, and decreased the need for adjunctive therapy in the studied patient population. The most common side effects included increased intraocular pressure and cataract progression.

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