

“Visual Impairment and Degeneration: A Road- map for Vision Research within Europe”



SUMMARY REPORT 01/03/2008 – 29/02/2012



*funded by the 7th Framework Programme of the European Union under
contract number HEALTH-F2-2008-200641*

“Vision researchers should never forget that beyond careers, publications and funding there are patients out there who need and expect a better quality of life: so please, researchers, once in a while close your eyes and imagine what impact an eye-opening research has on people affected by blinding diseases- and keep working for the good cause.”

Dr. Rainald von Gizycki, Honory President of ProRetina

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The impact on the notable accomplishments of Vision Research and Ophthalmology in clinical and basic research and patient care in Europe are obviously underestimated in comparison to other areas of the life sciences and medicine. This lack of visibility to political decision makers, the general public, private patrons and public funding bodies is detrimental to the European vision community.

To address this issue the European FP7-supported Coordination and Support Action “Visual Impairment and Degeneration: A Road-map for Vision Research within Europe (‘EuroVisionNet’)” aimed to coordinate and consolidate Vision Research activities and policies in order to overcome this national fragmentation.

The main objectives addressed under this action were:

- Better definition and acceptance of Vision Research within the scientific community
- Overcome the existing fragmentation of European Vision Research efforts
- Reduce duplication of research efforts
- Increase communication between clinical and basic researchers
- Foster collaborations between academic research and industry
- Support clarity regarding national and international policy mandates relating to clinical research activities
- Develop a better educational concept in the vision research community

The main results were:

- Bringing together the coordinators of European funded research projects
- Raise awareness for age-related blinding disorders and rare eye diseases, that have a major impact on the European society
- Development of better Private-Public-Partnerships in Vision Research
- To stress the importance of professional clinical trials in ophthalmology
- Round table of the major European ophthalmological societies
- Importance to disseminate research results, perform professional information policies and the better integration of patient organizations
- Development of better career paths for young investigators

In summary; ‘EuroVisionNet’ opened a first opportunity to better integrate the European Vision Research and Ophthalmology community. Further steps may be necessary to give this specific field a visibility it deserves according to the societal challenges in the near future.

1 'EuroVisionNet' brought together the scientific coordinators and the major actors of research projects concerned with visual impairment and degeneration funded through the European Union research programme FP5 and FP6. The **"COORDINATORS MEETING"** in Brussels (06-2009) provided an exciting overview of different European funded vision-related research project of the past and present. 16 coordinators exchanged best-practice models and started an interdisciplinary dialogue for future cooperation.



2 A Conference on the **"AGEING EYE"** was organised and took place in Bonn, Germany, on March 20-21, 2009. World-leading experts in the fields of epidemiology, health economics, age-related macular degeneration, glaucoma, mechanisms of ageing, and stem cell research met to discuss worldwide causes of blindness, state-of-the-art research of the pathogenesis of the major age-related eye diseases and their socioeconomic impact.



3 'EuroVisionNet' in association with the European Science Foundation (ESF) and Foundation Voir et Entendre organized a Conference in Biomedicine entitled **"RARE DISEASES: Hearing and Sight Loss"**. The Conference was held in Sant Feliu de Guixols (Costa Brava), Spain on November 22-27, 2009. It was chaired by Prof. Christine Petit (Institut Pasteur, Inserm, Paris, France) and Prof. José-Alain Sahel (Institut de la Vision, Paris, France).



The Conference focused on current advances in the research on the relationship between auditory and visual sensory systems. Special attention was paid to the significant progress in understanding the pathogenesis of the hearing and sight loss, and the recent advances in the development of therapeutic approaches.

4 To overcome the apparent lack of communication and motivation in the European vision research community that is needed to collaborate with industry and other potential funding and research partners activities to foster **“PUBLIC PRIVATE PARTNERSHIPS”** were implemented. This lack is apparent when evaluating the funding portfolio/sources used to support basic and clinical research activities within European academic and medical institutions. The European vision research institutions must be aware of the benefits of developing private and public partnerships.



5 The purpose of the White Paper **“TRANSLATIONAL RESEARCH IN OPHTHALMOLOGY AND VISION SCIENCES IN THE EUROPEAN UNION”** is to stimulate the process for translational research between the European Centres and to synergize multidisciplinary and interdisciplinary clinical and translational research. Translational research, usually called “bench to bedside”, applies discoveries generated through basic science research to the development and testing of preventive and treatment interventions and vice versa. Translational research may be seen as a five-phase model of intervention research that is commonly used to describe the continuum of biomedical research, from basic to applied science.

6 To maximize partnership opportunities with existing European societies and national organizations members of 51 national and European societies were invited to participate in the **“EUROPEAN VISION SUMMIT”**, a 2-day exploratory workshop ‘Towards the Future of European Vision Research’, which took place in Venice on June 16-17, 2008. 26 delegates representing 24 national institutions and European organizations attended the summit. The remaining two attendees were from ARVO (Association for Research, Vision and Ophthalmology) and the National Eye Institute in Washington, DC, USA.



7 The "YOUNG RESEARCHER VISION CAMP"

was the first of its kind in the field of Vision

Research in Europe. It gave young researchers (MSc students, PhD students, and early postdocs) the opportunity to present themselves and their work to fellow researchers and allowed them to build and strengthen personal networks in an international environment. 35 young researchers gave oral presentations and 44 young researchers presented a scientific poster. Apart from presentations and posters, there were two keynote lectures (held by Dr. Dusko Ilic, London, UK and Prof. Craig Smith, Novartis Pharma AG).



8 The consolidated "EUROPEAN VISION CONFERENCES" in London (27 MAY 2011) and Brussels (22 JUNE 2011) were both well attended and gave a good overview of current and future treatments for blinding eye diseases. The talks incorporated the most recent scientific developments of the post genomic area each presented by a renowned expert of the field. As part of the Consolidated Vision Conferences 2011 within



'EuroVisionNet' the suggested strategies should lead to sight-saving treatments, reduce visual impairment and blindness, and improve the quality of life for

people of all ages. The conference was implemented under the patronage of Dr. Charles Tannock, MEP.

9 "CONSOLIDATING PATIENT ORGANIZATIONS" were divided into four categories: Europe-focused (retina), international (retina), Europe-focused (vision-related), and international (vision-related). Out of the 103 patients organizations that were located, ten organizations (Europe-focused/retina), three international organizations (retina), and one international organization (vision-related) have submitted completed

questionnaires. Newsletters: topics relating to vision: cross-linking therapy, and irregularities. These articles languages to be able to reach organizations. Patient registry: 132 partners, a Pub-Med European countries), and Organization for Research and



Oncology Group. From these resources, 500 contacts have been identified. Of these 500 contacts, 15 nations are included, 49 patient databases have been incorporated, and 299,141 patients are represented. The Directory of Retinal Databases in Europe was successfully implemented.

These articles represent a variety of sleep, autoimmune therapy, corneal contact lens therapy for high corneal are translated into additional non-English speaking patient The progress is as follows: Contacted search (limitations: 1999-2009, involvement of EORTC (European Treatment of Cancer) Ophthalmic

10 “PUBLICATION OF THE WHITE BOOK “A VISION FOR HORIZON 2020 – A European Strategic Roadmap for Vision Research and Ophthalmology”. T.H. Wheeler-Schilling, J. Kremers, E. Zrenner (eds.), Shaker-Verlag, Aachen, 2012, ISBN 978-3-8440-0883-8. Introduced by E. Zrenner, C. Fasser and T. Wheeler-Schilling in the White book “A Vision for Horizon 2020” 75 experts out of twelve European countries (Spain, Switzerland, Italy, Norway, United Kingdom, Germany, Netherlands, Portugal, France, Sweden, Austria and Ireland) are covering all relevant subjects of Vision Research and Ophthalmology in order to predict future developments. The White Book aims at convincing the scientific community in Europe that ophthalmology is a discipline not only at the forefront of research but also at the forefront of translation of its scientific results into clinical practice. It should increase enormously the awareness of funding organizations and the concern of politicians about the further development of health and research in Europe concerning especially eye health.



11 Establishment of the “GATEWAY TO VISION RESEARCH IN EUROPE”. The purpose of the Gateway to Vision Research is to increase the visibility of Vision Research and Ophthalmology worldwide. Target groups are: clinicians, basic oriented researchers, patients and patient organizations, companies, scientific societies, funding agencies, political decision makers on the national and international level, governmental institutions. Statistics: Page impressions: 8580/m; Visitors 4185/m; Unique visitors 3.376/m (Google Analytics December 2011). The top 10 countries of visitors (1) USA, (2) Germany; (3) UK; (4) France; (5) Spain; (6) Sweden; (7) India; (8) The Netherlands; (9) Italy; (10) Canada (Google Analytics December 2011). Updates are performed on a daily basis – a respective newsletter on a monthly basis. Since its launch in October 2008 the Gateway to Vision Research has developed itself to one of the most influential web pages in the field. (www.vision-research.eu)



I. INTRODUCTION

The concept of the project 'Visual Impairment and Degeneration: A Road-map for Vision Research within Europe' (EuroVisionNet) aimed to coordinate and consolidate vision research activities and policies of the European vision research community in order to overcome the national fragmentation and to avoid duplication of work. EuroVisionNet supported and advised European societies and national organizations on both scientific and administrative issues. Offering educational and training workshops that cover both basic and clinical research was a clear added value. These workshops and seminars were tailored for the young as well as the highly advanced researcher.

'EuroVisionNet' addressed seven major challenges:

- Better definition and acceptance of vision research in the scientific community
- To overcome the still existing fragmentation of European research
- To reduce duplication of research efforts
- To increase communication between clinical and basic researchers
- To foster collaborations between academic research and industry
- To support clarity regarding national and international policy mandates relating to clinical research activities
- To develop a better educational concept in the vision research community

To address these issues four major objectives were defined within the European Vision Net proposal:

- Scientific integration of European vision research
- Collaboration with public and private sector
- Policies and guidelines for European vision research
- Information and knowledge transfer

The 'EuroVisionNet' workplan was organized as follows:

Objective I: Scientific integration of european vision research

Work package I:	Integration research projects from FP5 & FP6
Work package II:	The Ageing Eye
Work package III:	Rare Diseases

Objective II: Collaboration with public and private sector

Work package IV:	Fostering public and private partnerships
Work package V:	Strategies for re-engineering clinical research on vision including clinical trials

Objective III: Policies and guidelines for European vision research

- Work package VI: Strategies for involvement with European organizations in vision research
- Work package VII: Education and Training in Vision Research. Consolidated “European Vision Conference”

Objective IV: Information and knowledge transfer

- Work package VIII: Patient organization involvement
- Work package IX: Development, implementation and management of web-based portal

II MAIN RESULTS

Work package I: Integration research projects from FP5 & FP6 - Organisation and implementation of the “Coordinators Meeting” (Brussels, Belgium; June 24-25, 2009)

The main objective of Work Package I was to bring together coordinators and key players of European Union funded projects in the framework programmes FP5 (1998-2002), FP6 (2002-2006) and FP7 (2006-2013) in the wider field of vision relevant research efforts. The “Coordinators Meeting” was held in Brussels, Belgium on June 24-25, 2009. This event provided an overview of the different research projects of the past and present, enhanced the dissemination of the results and fostered the exchange of information and practical experiences gathered in the projects. It started an interdisciplinary dialogue between researchers, clinicians and major stakeholders from the EC and European parliament in order to initiate a strategic discussion for future activities. Significant results were:

- Identification of 31 FP5 and 16 FP6 coordinators with Vision Research Projects
- Contact establishment with all coordinators via e-mail and telephone
- On-line form for project details send out (available via www.vision-research.eu)
- Reply of 16 coordinators to present their projects
- Establishment of the meeting programme
- Organisation and implementation of the “Coordinators Meeting” in Brussels

Covered projects were:

Photage | *Photoreceptor Dynamics in Age-Related Macular Degeneration. Consequences for early diagnosis*. Prof. Jan Kremers, Prof. Hendrik Scholl, Germany

PolExGene STREP | *Biocompatible non-viral polymeric gene delivery systems for the ex vivo treatment of ocular and cardiovascular diseases with high unmet medical need*. Prof. Etienne Schacht, Belgium

CRUMBS IN SIGHT | *Restoring Müller glia cell – photoreceptor interactions with Crumbs*. Prof. Jan Wijnholds, The Netherlands

CORTICAL VISUAL NEUROPROSTHESIS FOR THE BLIND. Dr. Eduardo Fernandez, Spain

Fighting Blindness | *Prevention of Blindness: The structure and function of the visual system.*

Prof. Ulrich Schiefer, Germany

RETICIRC | *Circuit specific approaches to retinal diseases.* Dr. Maarten Kamermans, The Netherlands

RETNET | *European Retinal Research Training Network.* Prof. Shomi Bhattacharya, United Kingdom

RETRAINNET | *Prevention and therapy of blinding retinal neuro-degenerations.* Prof. Eberhardt Zrenner, Germany

MyEuropia | *European Training in Myopia Research.* Prof. Frank Schäffel, Germany

EVI-Genoret | *Functional genomics of the retina in health and disease.* Prof. José Sahel, France

EuroVisionNet | *Visual Impairment and Degeneration: A Road-map for Vision Research within Europe.* Dr. Thomas Wheeler-Schilling, Belgium

AMD-READ | *Age-Related Macular Degeneration: Assessment and Optimisation of Macular Function with Special Regard to Reading and Motor Control.* Prof. Susanne Trauzettel-Klosinski, Germany

Work package II: The Ageing Eye – The Ageing Eye Conference 20-21/03/2009

Work Package II – the Ageing Eye was designed to overcome the fragmentation of research efforts within Europe by encouraging and facilitating a means to develop and implement research priorities and strategies. A consortium of experienced international and multi-disciplined researchers and opinion leaders in the field of vision research would be invited to participate. To address this fragmentation problem, the Ageing Eye Conference took place in the Kunstmuseum Bonn on March 20-21, 2009. World-leading experts in the fields of epidemiology, health economics, age-related macular degeneration, glaucoma, mechanisms of ageing, and stem cell research met to discuss worldwide causes of blindness, state-of-the-art research of the pathogenesis of the major age-related eye diseases and their socioeconomic impact. The meeting stimulated exchange of ideas between research groups, discussion between patients and researchers, as well as between persons responsible for European research funding and the researchers themselves, and also stimulated the private-academic partnership by bringing together people from academia and industry.

Significant results were:

I. Global Perspective for Causes for Worldwide Blindness - Eberhart Zrenner

Serge Resniko (European Region, International Agency for Prevention of Blindness): Global Perspective for Causes for Worldwide Blindness – Trends and Challenges

Gary C. Brown (Wills Eye Hospital, Jerson Medical College, Philadelphia; Center for Value-Based Medicine, Flourtown, Pennsylvania, USA): Diabetic Retinopathy: An Emerging Cause of Global Blindness and Quality-of-Life Changes

II. Fundamental Processes of Ageing and Rejuvenation - Lenhard Rudolph

Oliver Brüstle (Institute of Reconstructive Neurobiology, University of Bonn; Life & Brain

Center and Hertie Foundation): From Pluripotent Stem Cells to Functional Neurons and Glia

Lenhard Rudolph (Institute of Molecular Medicine and Max-Planck-Research-Group on Stem Cell Ageing, University of Ulm): Molecular Causes of Ageing

Solon Thanos (Dept. of Experimental Ophthalmology, University of Münster): Mechanisms Controlling Regeneration of Ganglion Cell Axons in the Ageing Monkey Retina

Yvan Arsenijevic (Unit of Gene Therapy & Stem Cell Biology, Hopital Jules-Gonin, Lausanne): Which Retinal Stem Cells for Retina Repair?

III. AMD – Age-Related Macular Degeneration - Frank G. Holz

Macdonald Curran (Macular Disease Society UK, AMD Alliance International): The Patient Eye

Frank G. Holz (Dept. of Ophthalmology, University of Bonn): Dry Age-Related Macular Degeneration - New Perspectives and Future Directions

Caroline Klaver (Dept. of Ophthalmology, Erasmus Medical Center, Rotterdam): Diet and Genetic Susceptibility in Age-related Macular Degeneration

Philip Luthert (Institute of Ophthalmology, University College London): Models of Age-related Macular Degeneration

Victor Chong (Dept. of Ophthalmology, University of Oxford): Biomarkers in AMD

Manuel Hallen (European Commission, Brussels): 'Health' in FP7 - A focus on the Translation of Knowledge into Applications

IV. (Primary Open-angle) Glaucoma - Paulus de Jong

Paulus de Jong (Netherlands Institute for Neuroscience, Amsterdam): Slippery Roads-towards Disentangling Glaucoma

Ulrich Welge-Lüssen (Dept. of Ophthalmology, University of Erlangen-Nuernberg): Ageing as Risk Factor for Glaucoma

Norbert Pfeiffer & Christian Wolfram (Dept. of Ophthalmology, University of Mainz): Ageing and Primary Open-Angle Glaucoma

Nomdo M. Jansonius (Department of Ophthalmology, University of Groningen)

V. Socioeconomic Impact of Ageing Eye Diseases and Visual Rehabilitation - Gary C. Brown

Melissa M. Brown (Leonard Davis Institute of Health Economics, University of Pennsylvania; Dept. of Ophthalmology, University of Pennsylvania School of Medicine, USA): Value-Based Paradigm in Care of the Visually Disabled

Christina Fasser (Retina International, Zürich): Rehabilitation - A Patient's Perspective

Susanne Trauzettel-Klosinski (Centre for Ophthalmology, University of Tübingen): Rehabilitation of Reading Ability in AMD Patients

Gary S. Rubin (Institute of Ophthalmology, University College London): Visual Rehabilitation for Patients with Central Scotomas

Hans-Werner Wahl (Dept. of Psychological Ageing Research, Institute of Psychology, University of Heidelberg): Fundamentals of Psychological Adaptation to Age-related Vision Loss: Practical Implications

Work package III: Rare Diseases -22-27/11/2009

The European Science Foundation (ESF) in association with EuroVisionNet and Fondation Voir et Entendre recently organized a Conference in Biomedicine entitled “Rare Diseases II: Hearing and Sight Loss” (www.esf.org/conferences/09295). The Conference was held in Sant Feliu de Guixols (Costa Brava), Spain on November 22-27, 2009. It was chaired by Prof. Christine Petit (Institut Pasteur, Inserm, Paris, France) and Prof. José-Alain Sahel (Institut de la Vision, Paris, France). The Conference focused on current advances in the research on the relationship between auditory and visual sensory systems. Special attention was paid to the significant progress in understanding the pathogenesis of the hearing and sight loss, and the recent advances in the development of therapeutic approaches. The scientific program was conceived to present and discuss biochemical, genetic and physiological parallels between the two sensory systems, hearing and vision, as well as the common pathophysiological pathways. Cellular and molecular mechanisms underlying retina (the light-sensitive tissue of the eye) and cochlea (the auditory sensory organ) development and functions were a main focus of the talks and the discussions. Development of the sensory organs and evolution of the two sensory systems were reviewed also in the perspective of understanding how the sensory information from the two systems is integrated and of identifying the potential targets for pathological disruption. Rare diseases characterized by hearing and sight loss (ciliopathies, retinopathies, Usher syndrome) were in the focus of the conference. Genotype/phenotype correlations were revealed. New horizons in understanding the pathophysiological mechanisms in order to find therapeutic targets were communicated. Mechanisms of crucial importance, such as oxidative stress, were emphasized as possible targets for future therapies. Discussions on the continuum between fundamental science and applied medicine took the attention of the audience. Animal models of rare diseases were presented in the prospect of translation of basic science advances to tangible benefits in the clinical practice. Time was devoted to a deep reflection on therapies under development such as prosthesis, gene therapy, and new pharmacological and stem cell options. Keynotes lectures were held by 45 invited speakers, who are opinion leaders in the field of rare diseases affecting vision and hearing. The scientific program also included eight selected short talks and 51 posters covering both fundamental and clinical science. Three prizes for best poster presentations were awarded after a challenging competition. The Conference afforded an excellent opportunity to exchange ideas and opinions, communicate scientific information, and initiate new collaborations in a warm and friendly atmosphere. It also offered the occasion to listen to patients expectations.

Work package IV: Fostering public and private partnerships

The basis of Work Package IV was an apparent lack of communication and motivation in the European vision research community that is needed to collaborate with industry and other potential funding and research partners. This lack is apparent when evaluating the funding portfolio/sources used to support basic and clinical research activities within European academic and medical institutions. The motivation and need for diversifying the research funding portfolio used to support all basic and clinical research at academic institutions simply do not exist in Europe. The reason is that most academic institutions mainly rely on federal funding. Hence, many European clinicians and researchers do not see the advantage of engaging with other possible funding or research collaborators besides their national or European governmental sources. Furthermore, many European researchers believe that receiving industrial funding is not desirable because the funding is not peer-reviewed and might affect the scientific independence. However, as exemplified in the United States, collaboration with industry and other “outside” entities would substantially benefit European vision research by providing more opportunities. These benefits will be further identified and disseminated through the workshops that this WP facilitates.

Based on prior experience of attending lectures (>30 people) and workshops (<30 people), the WP4 leadership decided that to create an environment for discussion between the participants as well as the speakers, a workshop would be the ideal platform for this inaugural event. Additionally, to increase the likelihood of representation of multiple institutions using a limited budget, the leadership also decided to plan the workshop to coincide with a popular vision research congress (e.g. ARVO). Therefore, on Sunday, May 2, 2010, the private and public partnership (PPP) workshop was held in conjunction with the ARVO 2010 congress. A total of 26 participants from the United States and European countries confirmed, and they represented six nations. To increase the possibilities of private and public partnership matches, the leadership tried to balance the audience with academic institutions, industry and other invested parties (e.g. governmental institutions, patient organisations, clinical research organisations, intellectual property and fundraising specialists, etc.). From these efforts, the participants represented the following: 13 academic institutions, 9 companies, 1 patient organisation, and 1 governmental institution. The biggest draw for the participants was the selection of the confirmed speakers. In developing the invited speaker list, the WP4 leadership agreed that it was imperative to have both European and American speakers. And, these speakers should represent a wide range of areas relating to establishing directed research projects with industrial partners and governmental funding sources. Therefore, several factors were considered in the final selection: 1) European academic researcher with knowledge and/or affiliation to EVI, 2) industrial representative with experience working with academia, 3) clinical research experience, especially relating to FDA and EMEA regulatory requirements, and 4) a funding source (e.g. private or public). One obstacle was to define the right forum for an appropriate

meeting. We considered organizing an independent meeting and organizing a satellite meeting at a networking fare like EurOBio. We rejected these possibilities because of the negative cost-benefit ratio (of an independent meeting) and because of the risk of not reaching the appropriate audience (at a Biofare). As mentioned above, we decided to have meetings at conferences with the highest likeliness of attracting the appropriate audience. Once this decision was made, the only obstacles that were faced were purely administrative. When collaborating with ARVO, time and effort needed to be dedicated to demonstrate that there would not be a conflict of interest with ARVO's existing advocacy luncheon with a similar theme and with other ARVO activities. In the end, ARVO agreed that there was no conflict and even agreed to join forces. A future collaboration for 2011 is underway. The only adaptation of this program was that the first workshop was held one year ahead of schedule. The online report for 2010 has been uploaded on the vision-research.eu portal. Therefore, a follow-up workshop took place in 2011 at ARVO. An update of the first workshop was provided regarding potential collaborations between academic organizations and industrial partners.

Work package V: Strategies for re-engineering clinical research on vision including clinical trials

In order to accelerate and strengthen the clinical research process and to stimulate translational research that is to translate basic laboratory discoveries into the reality of improved patient care, which will indirectly increase the quality of life for many people in the European Union, partner 5 has proposed to develop a Network of Centres with active Laboratory Research Program and with dedicated Clinical Research facilities. A first meeting was organized in Coimbra, Portugal on 19 and 20 June 2008. European Clinical Research Centres were identified and invited to participate in the "Network of Translational Research Centres in Ophthalmology and Vision Sciences". The interested Centres have signed a Letter of Intent and a list was created. Currently the "Network of Translational Research Centres in Ophthalmology and Vision Sciences" has 11 Centres, from 9 European countries, all with full-active Clinical Trial Research Centers and active Laboratory Research Programmes. The European Science Foundation has just made public a Report on Investigator Driven Clinical Trials (IDCT) which strongly recommends the European Commission to fund Investigator-Initiated Clinical Trials and clearly states that there is need to create the appropriate environment such as network infrastructures to perform IDCT. During the 2nd period a questionnaire to characterize a Translational Research Centre and foster Translational Research in Vision and Ophthalmology in Europe was sent around in July, 2009 to 68 Centres and was also published on the EuroVisionNet website (<http://www.eurovisionnet.eu>). Until October, 2009 24 replies from Centres were collected.

The second meeting was organized and took place in Mainz, Germany on November 15, 2009. All 24 Centres that replied to the questionnaire were invited to participate. At this second meeting in Mainz 12 Centres were present. The questionnaire responses and conclusions were presented and followed by a discussion about topics and priority of themes to be addressed in the preparation of the “White Paper”. Following this second meeting, partner 5 started to write the “White Paper”. In order to receive contributions from the Network Centres a first draft of the “White Paper” was sent out in February, 2010 and a second draft in June, 2010. The final version of the “White Paper” is being reviewed according to the suggestions received and will be finalized and made available in December, 2010. Following the meeting in Mainz (Germany) on November 2009 the first draft of the “White Paper” was prepared. In order to receive contributions from the Network Centres this first draft of the “White Paper” was sent out in February 2010 and a second draft in June 2010. The final version of the “White Paper” was then reviewed according to the suggestions received and discussed within the Committee. As a deliverable of the WP5 the “White Paper on Translational Research in Ophthalmology and Vision Sciences in the European Union” was sent to the Coordinator of the Project on October 2010 and immediately made available through the EuroVisionNet website on http://www.eurovisionnet.eu/documents/pdf/EVN_WhitePaper_TranslationalResearch-2010.pdf. The purpose of this White Paper is to stimulate the process for translational research between the European Centres and to synergize multidisciplinary and interdisciplinary clinical and translational research. The White Paper and Translational Research in Ophthalmology was then particularly debated during:

- the Consolidated Vision Conference – Scientific Symposium, which took place in London, UK, on May 27, 2011
- the Consolidated Vision Conference – Parliamentarian Evening, which took place in Brussels, Belgium, on June 22, 2011
- the 6th EVICR.net Members Meeting, which took place in Ghent, Belgium, on November 14, 2011

An article on “Translational Research in Ophthalmology – A European Perspective” was published in 2011 in the European Ophthalmic Review (Cunha-Vaz J, Zrenner E: Translational Research in Ophthalmology: a European Perspective. Eur Ophth Rev 2011; 5(1):13-15)).

Work package VI: Strategies for involvement with European organizations in vision research

The mission of this Workshop and resulting documents is to promote and support vision research in Europe by assessing collaboration potential and maximizing partnership opportunities with existing European societies and national organizations relating to this field.

The purpose of this future collaboration will indirectly improve the quality of life of those affected by eye diseases on a European and global scale. The 12 existing societies that represent the vision research and ophthalmology on a European scale include the following: European Association for Vision and Eye Research (EVER), European Society of Ophthalmology (SOE), European Glaucoma Society (EGS), European Society of Ophthalmic Plastic and Reconstructive Surgery (ESOPRS), European Paediatric Ophthalmologic Society (EPOS), European Society of Cataract and Refractive Surgeons (ESCRS), European Ophthalmic Pathology Society (EOPS), European Strabismological Association (ESA), European Community of Ophthalmic Professors (EUPO), European Contact Lens Society of Ophthalmologists (ECLSO), European Vitreoretinal Society (EVRS), and the European Society of Retinal Specialists (EURETINA). The 21 countries with existing organizations that represent vision research and ophthalmology on a national level include the following: Austria, Belgium, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, The Netherlands, Norway, Poland, Portugal, Slovakia and Slovenia. Through identifying research priorities of major impact and the promotion of existing therapeutical approaches, this exercise would serve as the platform of an organized European entity by supporting all fields of vision research – not limiting to geographic boundaries, rare diseases, specific area of the eye, high impact eye diseases, disciplines, etc. Financially speaking, the coordinated effort will be able to maximize the vision research's potential of increased public and private funding in the field when approaching potential funding agencies or private institutes/companies as one corporate organization. The structure of the summit included a two-day workshop designed to combine national, European and international perspectives on vision research priorities. These perspectives would then be organized into a strategy paper on how to improve awareness about vision research and increase funding for this field. More specifically, the delegates were asked to divide into sub-groups and were given open-ended questions that prompted discussions. Lastly, each sub-group was asked to present their "harmonized" opinion on the proposed questions to the entire summit.

Main consensual conclusions

- (1) All delegates agreed to move forward with the efforts of the Eurovision Summit 2008 and the initiatives of the European Vision Institute as they relate to the increase of awareness and need to decrease the fragmentation among the national societies as well as European organizations in the field of vision research.
- (2) All delegates agreed to join the proposed "Alliance for the Advancement of Vision Research". The European Vision Institute will handle the administrative efforts relating to the formation of the alliance.
- (3) The president of the Slovenian Society of Ophthalmology and local organiser of EVER, Prof. Mark Hawlina, proposed that a roundtable be organised with the delegates of the Eurovision Summit 2008 at EVER 2008. An address by the EU Commissioner for Research is

scheduled for the EVER 2008 congress, and it will be structured in question-answer fashion, in order to help understand the needs of the vision research community. This occasion could be suitable for presenting to the EU Commissioner a common position document in respect of the future of Vision Research.

Preliminary action plan

To develop and distribute: "White Paper" based on the discussions of the European Vision Summit 2008

(1) To form the "Alliance for the Advancement of Vision Research"

Participants: All national societies, European organizations industry and potential funding partners Goal: To reduce national fragmentation that currently exists within the vision research community. Ultimately, the goal would be to speak with one voice in relation to the priorities and future objectives relating to the vision research community. Objectives: Use the FP7-funded web portal developed and maintained by the European Vision Institutes for information gathering, dissemination and impact purposes. This information would ultimately be used for impacting policy decisions and research directions.

(2) To compile data to develop a Standardized Statistics Sheet for vision research based on epidemiological figures

Participants: All organizations, societies, universities, institutes and practices in the field of vision science Goal: To provide a standardized sheet that will be used for information dissemination purposes Objective: To use the Johannes Gutenberg University of Mainz's national survey as the best practice model.

(3) To organize and conduct: Educational and Training Courses relating to business development

Participants: clinicians and researchers Goal: To diversify and increase funding opportunities to support the vision research community Objectives: Approaching industry for funding; Joint venture opportunities; Intellectual Property Rights proficiency.

Work package VII: Education and Training in Vision Research. Consolidated "European Vision Conference"

Education and training was an ongoing theme of all the work packages of the EuroVisionNet. Therefore, the work package leaders have worked together to support each other in achieving their deliverables. The kick-off event of WP7 – Education and Training was the interdisciplinary congress in June 5-6, 2008. The highlight of this congress was that the topic was able to bring together both clinicians and basic researchers. The second event was a joint collaboration with WP2 – Aging Eye Conference held in Bonn, Germany from March 20-21, 2009. Multiple disciplines were represented to provide scientific input on this single

topic. The Young Researcher Vision Camp was held on the Castle Wildenstein in Leibertingen, Germany from June 25-27, 2010. This "Camp" was the first of its kind in the field of vision research in Europe. It gave young researchers (MSc students, PhD students, and early postdocs) the opportunity to present themselves and their work to fellow researchers and allowed them to build and strengthen personal networks in an international environment. 35 young researchers gave oral presentations and 44 young researchers presented a scientific poster. Apart from presentations and posters, there were two keynote lectures (held by Dr. Dusko Ilic, London, UK and Prof. Craig Smith, Novartis Pharma AG) as well as an afternoon of round table discussions with senior scientists from different European countries (topics: Career opportunities - Academia versus Industry, Research - Family - Career, Career Development and Transferable Skills, Postdoc time abroad - where to go?). The abstract book is available online under <http://www.vision-research.eu/index.php?id=538>. Regarding the e-learning network, the recording of all the keynote talks of each congress have been done or currently planned. The concept is to stream the recorded talks on the vision-research.eu portal for post-congress viewing needs. Each of the keynote lecturers has or will provide a consent form to allow the recording and posting of the lecture on the portal.

The Consolidated Vision Conference I took place on May 27th, 2011 in London UK. The research partners in EuroVisionNet organised a symposium at the Euretina meeting 2011 in London. The symposium was chaired by Professor Moore from the Institute of Ophthalmology in London and Prof. Cunha-Vaz from the University of Coimbra in Portugal. The aim of the meeting was to discuss current and future treatments for retinal disease. Euretina was chosen as the forum for the symposium because of the high number of retinal specialists (over 3,000) that attended the meeting. The symposium was one of the main symposiums of the meeting and we were pleased to find there was a very large audience. The meeting was started by a talk from Dave Shima who spoke about the basic science behind the development of novel anti-VEGF agents which have proved successful in the treatment of age-related macular degeneration. He also discussed areas where treatment could be improved and what new therapies may be on the horizon. Thomas Gardner from Penn State College of Medicine, USA, gave an excellent talk on the pathogenesis, current treatment and treatments that may be in the pipeline for diabetic macular oedema which is a major cause of vision loss in diabetes. Frank Holtz, Professor of Ophthalmology at the University of Bonn discussed the management of the "dry" form of age-related macular degeneration – geographic atrophy. Professor Holtz emphasised the importance of careful imaging of the retina and the importance of careful natural history studies in advance of clinical trials. He also discussed the need for robust end points in clinical trials of novel therapies. Finally, he discussed current and future treatments for this common disorder. Prof. José Sahel opened his talk by discussing the options for treatment of inherited retinal disease and then focussed on the best approaches to preserve or rescue photoreceptors in early and mid stage disease. He explained that in some inherited retinal diseases where the

mutant gene is only expressed in rod photo receptors, the cones later die. He described his own work in trying to identify the mechanism of cone cell death and described the identification of a gene encoding a protein which is called rod-derived cone viability factor. He and his group have been working to try to develop treatments that will preserve cone function in the face of continuing rod photo receptor cell death. Professor Robert Maclaren from Oxford University discussed the current state of stem cell therapy for retinal disease. He discussed the major advances that have been made in the laboratory and in developing retinal pigment epithelial cells and photo receptor cells from stem cells and also the progress that has been made in encouraging integration of photoreceptors into degenerating retina. He was careful to point out that there was still a significant amount of basic science work that needs to be done. But he was optimistic that stem cell therapy would eventually be an effective treatment for retinal disease. The meeting closed with a talk by Eberhart Zrenner on the development of retinal prosthesis that can be used in advanced stages of inherited retinal disease when there has been near complete loss of the photo receptors. The retinal prosthesis work by stimulating ganglion cells in the retina directly. He described the two basic approaches that have been used: the epiretinal implant and the subretinal implant and discussed the advantages and disadvantages of each type of prosthesis. He then discussed the progress that has been made by his multi-disciplinary group in the University of Tübingen in developing the subretinal implant and described the early results of his clinical trial. The symposium was very well attended and overall gave a very good overview of current and future treatments for retinal disease.

The Consolidated Vision Conference II took place on June 22th, 2011 in the European Parliament. The 'Parliamentarian Evening on Finding New Treatments for Blinding Disorders' provided information for devising and implementing programs and projects for new therapeutic strategies to combat eye diseases that are currently difficult or impossible to treat. The talks incorporated the most recent scientific developments of the post genomic area each presented by a renowned expert of the field. As part II of the Consolidated Vision Conference 2011 within 'EuroVisionNet' the suggested strategies should lead to sight-saving treatments, reduce visual impairment and blindness, and improve the quality of life for people of all ages. The conference was implemented under the patronage of Dr. Charles Tannock, MEP. There were five speakers and an audience of sixty individuals, including Members of European Parliament and individuals from the European Commission. The meeting opened with a welcoming address from Dr Charles Tannock. Dr Tannock explained to the audience that he had trained at the Middlesex medical school in London as a doctor. The Middlesex medical school is now part of University College London. He had trained in Psychiatry and held a consultant position at University College Hospital London until he was elected to the European Parliament. He welcomed the participants to the European Parliament and emphasized how pleased he was to sponsor the meeting.

The opening talk was by Professor Eberhart Zrenner who set the scene by emphasizing what an important problem visual impairment was in Europe. He gave a brief introduction to the major causes of blindness in Europe including an estimate of the numbers of blind and partially sighted individuals living within Europe. He continued by emphasizing the importance of translational research to develop new treatments. He finished his talk by showing an example of how multi-disciplinary collaborations can develop new treatments. He described the advances that have been made in developing the retinal implant which allows patients who have lost the light sensitive cells (photoreceptors) in the retina to see again by stimulating the nerve fibres in the retina. Christina Fasser, the president of Retina International, an organisation of patient support groups and research charities, spoke about translational research from the patients' perspective. She emphasised the fact that patients are extremely keen to develop new treatments and are keen for international collaboration in the research effort to develop these treatments. The third speaker was Professor José Cunha-Vaz from Coimbra in Portugal who highlighted the need for collaboration across Europe for clinical trials. He gave an account of the clinical research network which is set up across Europe to develop the infrastructure for European-wide clinical trials. James Jorkasky spoke next. James is the Executive Director of the National Alliance for Eye and Vision Research. This is an organization which lobbies in the United States to increase funding for vision research. James gave a very informative and entertaining account of his role in supporting vision research in the United States and gave useful insights into how to lobby politicians to increase awareness of the need for vision research. He was careful to point out that there were significant cultural and other differences between Europe and North America, but there is much to be learnt from his experience in the United States. The final talk was by Professor Peng Tee Khaw, professor of Ophthalmology at the Institute of Ophthalmology and Moorfields Eye Hospital, London. Professor Khaw is Director of the National Institute of Health Research, Biomedical Research Centre in London. Like the other speakers, Peng emphasized the great importance of translational research and gave some important examples about how advances in basic science are now being translated into clinical practice.

Work package VIII: Patient organization involvement

Building relationships with patient organizations is fundamentally the most important component of information dissemination for patients. These organizations know where the patients are located and what types of diseases are prevalent in their geographical area. Without this useful information, the tracking of patients for clinical studies, treatment and basic educational materials relating to their diseases would be quite cumbersome and inefficient.

The work plan comprised of three main tasks: consolidating patient organizations relating to visually debilitating diseases, information dissemination in the form of newsletters and establishing a patient registry. Utilizing the human resources of patient organizations already affiliated with Retina International, many of the administrative tasks are being accomplished by these partners.

Results: Patient organizations were divided into four categories: European (retina), international (retina), European (vision-related), and international (vision-related). Eight European (retina) and one international organizations' information has been uploaded on the EuroVisionNet (EVN) web portal. During the interview process, a questionnaire was created and disseminated in English to ensure that the same information was being requested. Regarding information dissemination, articles for the newsletters have been written and translated into German, French and Italian. A scientific writer was hired to handle article selection and drafting of text for a patient audience. *Patient registry:* The progress is as follows: Contacted 132 partners, a Pub-Med search (limitations: 1999-2009, European countries), and involvement of EORTC (European Organisation for Research and Treatment of Cancer) Ophthalmic Oncology Group. From these resources, 500 contacts have been identified. Of these 500 contacts, 15 nations are included, 49 patient databases have been incorporated, and 299,141 patients are represented. The Directory of Retinal Databases in Europe was successfully implemented.

Obstacles: For the patient organizations, there were four main obstacles: locating the patient organizations, too much focus on retinal organizations, volunteer-basis structure of organizations and multiple languages (non-English speaking).

For the newsletters, three obstacles presented themselves: choosing newsletter topics, collecting / writing articles, and articles were too complex for layman reader (patient).

For the patient registry, the management of the enormous amount of information and the competing institutions for this type information are the initial challenges. The work plan of WP VIII comprised of three main tasks: Consolidating European and beyond patient organisations relating to visually debilitating diseases, information dissemination in the form of newsletters and establishing a patient registry. Utilizing the human resources of patient organisations already affiliated with Retina International, many of the administrative tasks are being accomplished by these partners. Out of the 103 patients organisations that were located, ten organisations (Europe-focused/retina), three international organisations (retina), and one international organisation (vision-related) have submitted completed questionnaires.

While two phases of emails, phone calls and interviews were conducted in Fall 2009 and Spring 2010, there was only a response rate of 15.5%. The difference between the two

phases is that in Spring 2010, the patient organisations were asked to complete their questionnaires via Internet as opposed to hard copy forms to be faxed or emailed. This change resulted in six additional organisations from the original nine that responded in Fall 2009. Additional ways to increase the response rate are: 1) to use the existing relationship with the European Patient Forum and 2) to meet with the individual patient organisations at an international congress on June 23, 2010 to verbally complete the forms.

Results

Newsletters:

Regarding information dissemination, articles for the newsletter have been written. Within the reporting periods at the following dates newsletters were issued:

October 5th, 2010; November 8th, 2010; December 3rd, 2010; January 14th, 2011; February 11th, 2011; February 23rd, 2011; April 1st, 2011; May 13th, 2011; June 7th, 2011; July 11th, 2011; August 29th, 2011; September 28th, 2011; October 27th, 2011; November 29th, 2011; December 19th, 2011; January 3rd, 2012 and January 24th, 2012. These information were provided by Retina International to their non-english speaking partner organizations for further dissemination in seven languages.

Work package IX: Development, implementation and management of web-based portal

The objective of this Work Package was not only to accompany and facilitate the coordination of the activities of the EuroVisionNet project as a whole, but also to foster the communication and to ameliorate the transparency regarding the activities of the whole European Vision community, especially supporting the young researchers and patient organizations.

Status Quo

- Status: Running
- 225.000+ Page Impressions
- 37.000+ Unique Visitors
- 530+ Individual Pages
- 550+ News-Articles
- 360+ Events and Dates
- 120+ People Profiles
- 90+ Research Group Profiles

Significant results

- On-going development of the portal “[www. vision-research.eu](http://www.vision-research.eu)”
- Huge increase of numbers of visitors and page impressions

- Promotion of the portal at several meetings and conferences by means of oral presentations and distribution of promotion material (leaflets and flyers)
 - Ageing Eye Conference, 2009, Bonn, Germany
 - Coordinators Meeting, 2009, Brussels, Belgium
 - Euretina Board Meeting, 2010, Dublin, Ireland
 - Exploratory workshop “Fostering Public Private Partnerships (PPP) in Vision Research”, 2010, Ft. Lauderdale, USA
 - World Ophthalmology Congress 2010, Berlin, Germany
 - Young Researcher Vision Camp, 2010, Castle Wildenstein, Germany
 - International Myopia Congress 2010, Tuebingen, Germany
 - XXVIII Congress of the ESCRS 2010 (European Society of Cataract and Refractive Surgeons), Paris, France
 - DOG 2009 - Annual Meeting of the German Ophthalmological Society 2009, Leipzig, Germany
 - EVER 2009 - Annual Meeting of the European Association for Vision and Eye Research, Portoroz, Slovenia
- Presentation of development of the web portal during the EuroVisionNet Annual Meetings 2009, 2010, 2011 and 2012

Featured Content

- Photo Competition 2009, 2010, 2011 and 2012
- Promotion for Young Researcher Vision Camp 2010 (microsite, electronic registration, news channel, photo gallery)
- Visionary of the Quarter
- Young Researcher in Focus
- Interviews with stakeholders in the field of vision research (5-to-5-interview)
- Publication of the year 2009, 2010, 2011 and 2012
- ARVO 2009 Poster Presentation
- Presentation of the candidates of the Election for the European Parliament

Target groups are: clinicians, basic oriented researchers, patients and patient organizations, companies, scientific societies, funding agencies, political decision makers on the national and international level, governmental institutions. Statistics: Page impressions: 8580/m; Visitors 4185/m; Unique visitors 3.376/m (*Google Analytics December 2011*). The top 10 countries of visitors (1) USA, (2) Germany; (3) UK; (4) France; (5) Spain; (6) Sweden; (7) India; (8) The Netherlands; (9) Italy; (10) Canada (*Google Analytics December 2011*). Updates are performed on a daily basis – a respective newsletter on a monthly basis. Since its launch in October 2008 the Gateway to Vision Research has developed itself to one of the most influential web pages in the field. (www.vision-research.eu)

Work package X: Project Management

The main task of work package 10 is to manage and to coordinate the 'EuroVisionNet' project in terms of its strategic, administrative and financial implementation. Together with the involved partners, the management and coordination activities within the 2nd reporting period were achieved. Results:

- 1st and 2nd Annual Meeting organised and implemented (1st AM: 19.03.2009 in Bonn, Germany; 2nd AM: 08.06.2010 in Berlin, Germany). The 3rd and Final Annual Meeting were organized and implemented (3rd AM: 27.05.2011 in London, UK; The final EuroVisionNet Meeting: 18.02.2012 in Abu Dhabi, VAE)
- Numerous individual emails and telephone contacts were processed during the reporting period
- Collection, completion, check and submission of the 1st , 2nd and 3rd periodic report and of the Financial Statements of all 9 / 10 EuroVisionNet beneficiaries (Forms C)
- Amendment No. 1 to the EuroVisionNet Grant Agreement (termination of beneficiary 3 (INSERM), addition of beneficiary 10 (FSCHS)): Revision of the GPFs, revision of Annex I to the GA, request for all necessary documents, forwarding of all documents to the Edu-GLIA Project Officer
- Day to day administrative and financial management of the project and fine tuning with the EuroVisionNet Project Officer and Financial Officer of the European Commission. Financial management includes (i) distribution of funds and (ii) co-operation with the respective financial bodies of each partner institution
- Collection and consolidation of the Private-Public Partnership Workshop white paper
- Publishing a White Book: " A Vision for Horizon 2020 – A European Strategic Roadmap for Vision Research and Ophthalmology" (see attachment)
- Ongoing updates of the webpage of the project EuroVisionNet
- Presentation of the work packages, project events, distribution of all relevant information
- Promotion of the web-based portal "vision-research.eu" at several meetings and conferences by means of oral presentations
- Creation and distribution of promotion material (leaflets and flyers)

Work package I: Integration research projects from FP5 & FP6

The major impact was to bring together 16 coordinators of European projects in order to discuss future strategies and to exchange ideas for a better representation of vision research activities within future European framework programmes. Several topics were identified for further promotion:

Epidemiology: Eye disorders have been identified as the fastest growing number of disorders in health care mostly due to the increasing number of elderly people in Europe. The United States have recognized this problem and have developed an action program strongly supporting research in vision sciences and ophthalmology.

Age related problems and role of ophthalmology: Loss of vision disables more and more people which is a major costly problem for society. Maintenance and restitution of vision is the main goal of ophthalmology. More research and development enables ophthalmology to solve the problems.

Allocation of research funds should go to most promising areas: Most recent developments that are close to clinical supplication should be considered in funding genuine and interdisciplinary research in vision sciences and ophthalmology.

Cooperation with industry is based on the direction and state of research: Industrial partners have to be convinced for a better support of translational research.

Novel directions of prevention and therapy: Gene therapy, stem cells, retina implants, electronic devices for rehabilitation are already explored in clinical studies worldwide. Small molecules to be applied according to genetic make-up in personalized medicine are already considered and explored for therapy.

Work package II: The Ageing Eye

The baby boom generation together with a longer life expectancy will have an enormous impact on the prevalence of age-related eye diseases and the incurment of costs to our economy. The impact of visual impairment and blindness in the elderly is already tremendous for all European countries. Hence, additional funds are needed not only for the treatment of age-related eye diseases but also and most importantly to intensify research in order to prevent blindness in the elderly. In recent years interdisciplinary research has greatly added to our understanding of disease mechanisms in age- related macular degeneration (AMD), glaucoma, diabetic retinopathy and other retinal vascular diseases. However, there are many unmet needs as the following examples will show. While a certain proportion of patients with AMD and secondary neovascularization in the central retina can be effectively treated with anti-VEGF (vascular endothelial growth factor) therapy, many patients still loose vision despite being given the appropriate treatment. Research into why they do not respond as

well as for alternative more effective approaches needs to be intensified. In addition and based on a better understanding of the underlying molecular mechanisms new treatments

need to be developed to intercept pathogenetic pathways responsible for the development of dry AMD. No treatment is yet available for patients suffering from advanced dry AMD (“geographic atrophy”). In patients over 80 years of age the advanced stages of dry AMD are four times more frequently the cause for severe loss of vision than neovascular AMD.

A better comprehension of the genetic bases is not only needed for the onset and progression of AMD, but also for glaucoma and diabetic retinopathy. Large cohorts of patients need to be systematically phenotyped including high resolution imaging technologies in addition to population-based studies in order to identify relevant genetic and environmental factors. Furthermore, ocular biomarkers need to be determined and validated for more accurate estimations of disease progression and to individualize currently available as well as future treatments. Molecular imaging is a particularly relevant research area to provide new ocular biomarkers detecting disease activity in AMD as well as the other above mentioned diseases of the elderly. The earlier a diagnosis may be achieved the better the chances to prevent loss of vision by timely intervention.

Moreover, further research is needed to develop long acting drug delivery (LAD) systems. Particularly for elderly patients adherence is often difficult and present treatments such as anti-VEGF therapy have to be delivered in short intervals (e.g. monthly) with serial repetitive intraocular injections. Due to immobility and dependence on relatives, favourable outcomes often cannot be achieved because patients are unable to return to clinics for monitoring and treatments as frequently as required. Recent registries in Germany, the United Kingdom and Belgium have demonstrated that there is an overall significant undertreatment of patients with neovascular AMD with subsequent avoidable visual deterioration. The development of long acting drug delivery devices would substantially reduce the number of visits to clinics and thus significantly improve functional outcome. Finally, more effective rehabilitative approaches have to be developed particularly adapted for the needs of elderly people.

Work package III: Rare Diseases

Retinitis Pigmentosa (RP) is the most common inherited retinal disease that affects more than 1.500.000 people worldwide. Irreversible loss of vision is the common characteristic of the genetically heterogeneous group of inherited retinal degenerations. A key challenge to clinicians over more than a century since the condition was described lies in the fact that in all affected patients the loss of scotopic (rod) function is followed, after an average 10-15 years, by irreversible loss of cone, i.e. photopic, central and peripheral vision. More than 150 causal genes have been identified so far in retinal degenerations. These include mutations in the visual pigment rhodopsin, enzymes of the phototransduction cascade, and peripherin/rds and ABCR, the structural and trafficking proteins. Mutations less often affect genes expressed in the adjacent retinal pigment epithelium, such as CRALBP, RPE65 or Mertk. The inheritance can be either autosomal dominant, autosomal recessive, X-linked recessive or mitochondrial. This large number of genes and the dominant inheritance is a major challenge for corrective gene therapy. Medically, because RP remains a currently

untreatable disorder, preventing cone cell death is a very promising therapeutic approach: Even when 95% of the cones have been lost in patients with a macular disease specifically affecting the cones, the vision remains substantial.

Rare eye disorders have a significant health impact causing more than 60% of childhood cases of blindness. Since eye abnormalities are also present in one third of the rare systemic diseases (which means that about 1800 syndromes involve eye disease as a component) they represent a critical public health issue. Retinitis Pigmentosa (RP) and other retinal degenerative diseases affecting more than 1.500.000 people worldwide are part of a long list of orphan diseases for which no treatment is currently available. They constitute a heterogeneous group of disorders having common characteristics that lead to permanent and potentially severe loss of vision. Advances in understanding the mechanisms that underlie these pathologies will provide rationale for development of therapeutic strategies and novel approaches for these currently untreatable diseases.

Work package IV: Fostering public and private partnerships

In the past, research in the area of ophthalmology and visual sciences in Europe performed in academia and non-profit organisations on the one hand and in industry on the other hand was strictly separated. The goals were quite different: industrial research was strongly focussed on developing a product or service whereas the goal of academic research was the gain of basic knowledge. The two could complement each other but there was no need for collaboration; on the contrary a collaboration was considered undesirable because it would distract from the particular goals. In the meantime, things have changed. The goals on both sides have become quite demanding. As a result an isolated group with a limited repertoire of methods and expertises can hardly survive neither in academia nor in industry. Instead, extensive collaboration is required also with scientists with different backgrounds and research goals. In addition, the gain of knowledge makes a shift in paradigms necessary and possible. This may have pragmatic reasons: In academia, there is an increasing need to explore new roads for financial support. A collaboration with industrial partners may be such a source for financial support. Moreover, the idea that scientific research may have a practical application in the form of a product with which revenues can be obtained is not regarded to be unwanted anymore. On the contrary, it can be desirable. On the other hand in some industrial branches (e.g. the pharmaceutical industry) it is increasingly difficult to bring new products on the market, despite considerable research efforts and financial commitments. A collaboration with basic researchers may help to fill the pipeline and open up new roads.

One future solution will be to consider a change in paradigms. Research will have to be performed in a more holistic manner, integrating the results of all known data. Through this integration, new properties of the visual system will emerge giving a possibility to get a more complete description of its function and dysfunction. This can not be exclusively done

experimentally. Computer based simulations will be crucial in describing the complete system. To come to a realistic description it will be important to acquire as much data as possible that can be used in the computer models and simulations. The Blue Brain Project (bluebrain.epfl.ch) is an example in which an integration can be achieved in neurosciences. Similar models are getting available in visual science as well. They will be extremely important in disease related research. They can make tedious and expensive experimental work obsolete, because they can help concentrating upon the avenues that seem to be most promising. They will never replace all experimental work but they may help to identify and eliminate the less obvious experiments, thereby solving large parts of the problems mentioned above. Most importantly, this will force academic and industrial researchers with many different backgrounds to collaborate. These were my main considerations to found with colleagues with both industrial and academic backgrounds a company (Rhenovia Pharma) that offers these computer based models and simulations in the field of neuroscience (including vision research).

Work package V: Strategies for re-engineering clinical research on vision including clinical trials

Medical research is the basis for optimal patient treatment in hospitals and healthcare throughout the world. Patient-oriented research carried out in high-quality, multinational clinical studies will reduce fragmentation and duplication of research in Europe. Efficient patient-oriented research requires both specialized competences and a supporting infrastructure. However, at present, there is a clear need for infrastructures that support patient investigations, database management, quality assurance, monitoring and regulatory affairs. Clinical investigators often lack the expertise needed to plan all the necessary resources, requirements and agreements before starting a clinical trial. Clinical investigators need to have access to robust data collection methods. Loss of vision is a major threat for the aging European society as its incidence quickly increases with age. While cataract is handled well by microsurgery, other blinding conditions such as age-related macula degeneration, retinal dystrophies, glaucoma and diabetic retinopathy cannot be treated well. On the other hand, knowledge about endogenous and exogenous factors increases rapidly in basic research, opening new pathways to therapy. The European Vision Institute Clinical Research Network (EVICR.net) was created as a network of European Ophthalmological Clinical Research Sites, dedicated to perform clinical research in ophthalmology with the highest standards of quality, following the European and International Directives for Clinical Research according to harmonized Standard Operating Procedures (SOPs) compliant with ICH GCP Guidelines. The Network was established in 2004 and since 2010 EVICR.net is a legal entity established as an independent European Economic Interest Grouping (EEIG). Its centralized infrastructure is located at AIBILI, Coimbra, Portugal which functions as the Coordinating Centre with Contract Research Organization (CRO)

functions necessary for the management of multicenter clinical trials. At present the EVICR.net has 76 Centres members from 16 European Countries

Work package VI: Strategies for involvement with European organizations in vision research

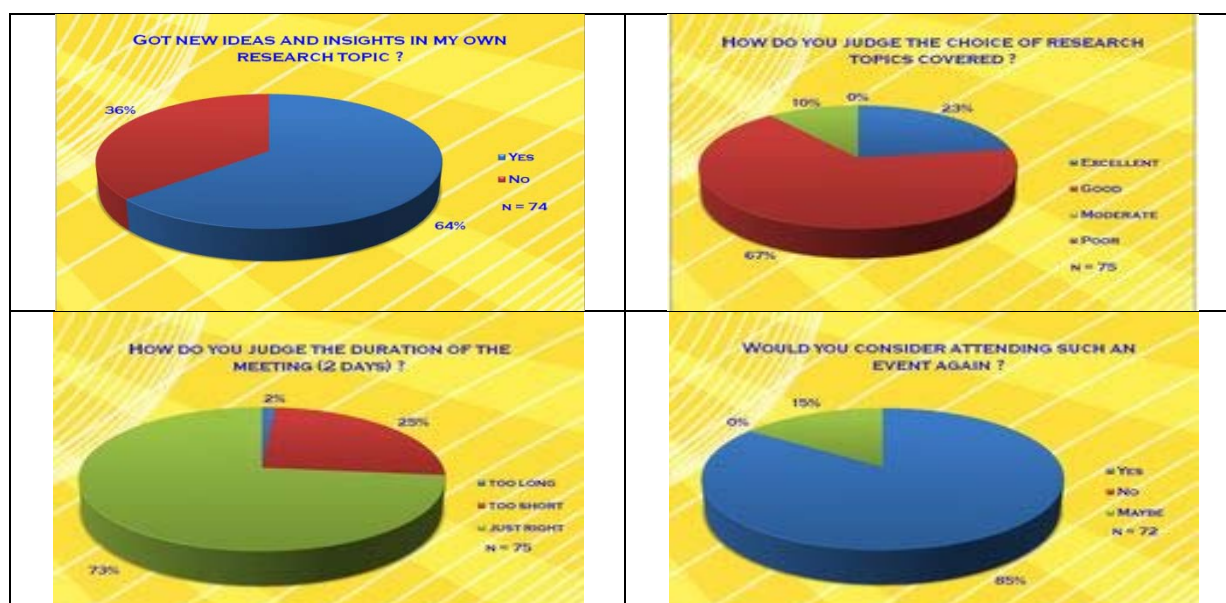
The main impact was that there are regular contacts between the following organisations / societies:

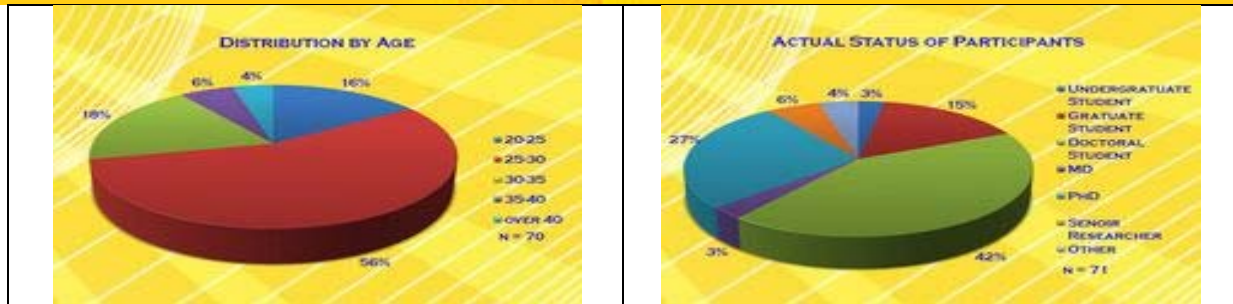
- EURETINA, European Society of Retina Specialists
- EVER, European Association for Vision and Eye Research
- EGS, European Glaucoma Society
- SOE, European Ophthalmological Society
- ESCRS, European Society of Cataract and Refractive Surgeons

There was a Joint note of the European Vision Institute (EVI) and the European Association for Vision and Eye Research (EVER) to the previous EU Commissioner of Research Dr. Janez Potocnik on October 3rd, 2008 in Portoroz, Slovenia in respect to Fighting Vision Impairment and Blindness: A priority for the European citizens indicating that the EU-Population aged 80 and above will more that double between 2005 and 2050. There is a projected increase of the prevalence of blindness and low vision in EU by 30 percent by the year 2050.

Work package VII: Education and Training in Vision Research. Consolidated “European Vision Conference”

There was a tremendous impact from the ‘Young Researchers Vision camp’ and the ‘Parliamentary Hearing’ in the European Parliament. Just to mention some evaluation results Full details under <http://www.vision-research.eu/index.php?id=570>





"I expected that it would be good but it was excellent!" [KB]

"It was a pleasure and an honour! From my point of view it was a great success! A lot of networking and good science talks in a very inspiring atmosphere!" [SH]

"I hope there will be continuation which I would be more than happy to participate in." [AP]

"It's good to hear young researchers speak for a change instead of the Silverbacks"; [SM]

"The tenure of the questions, the size of the group and the very high quality of young researchers (these will be the leaders of the future in ophthalmic research and care provision) was outstanding." [CS]

"The Vision Camp was great, and I enjoyed it very much." [EK]

Blindness is one of the most feared health problems in our present society. It also has deep socio-economic and public health implications with a strong age-related component. Currently, millions of Europeans are threatened by blinding untreatable eye diseases with an associated loss to the economy of several billion Euros each year. The 'Parliamentarian Evening on Finding New Treatments for Blinding Disorders' has provided information for devising and implementing programs and projects for new therapeutic strategies to combat eye diseases that are currently difficult or impossible to treat. The talks incorporated the most recent scientific developments of the post genomic area each presented by a renowned expert of the field and educated stakeholders from various fields.

Work package VIII: Patient organization involvement

Looking back to the last 30 years, we do see an enormous progress, but treatments are still lacking. The eye, the window to the world, is one of the most precious senses human beings have. It allows social interactions, learning and achieving in the very complex world of today. The social and economic burden of untreatable blindness and therefore unavoidable blindness will be increasing dramatically due to the demographic development within the next 20 years. Age related macular degeneration is the main cause of blindness in the industrialized world. The introduction of anti VEGF treatments for wet AMD was a revolutionary step forward. The first time in the history of ophthalmology this devastating disease could be stabilized and in certain cases vision could be even improved. However, it is still a reality that not all patients in Europe have access to this sight saving treatment. Furthermore, the huge majority of patients with dry AMD or geographic atrophy still cannot

be treated because of lack of proven and efficient treatment. The same applies for patients with inherited retinal degenerations. However, we are in the lucky situation that a number of treatment trials are already going on and we do hope that these treatments will be efficient and if so will reach the market. Such treatment trials are made e.g. in gene therapy for LCA, Choroideremia, Usher Syndrome and others to follow. Furthermore, drug therapies using growth factors such as CNTF to protect the retina from further degeneration are already going into clinical phase 3. Hope for already blind patients are around with the introduction of artificial vision systems into the market in the near future. The first treatment trial with stem cells has already taken place for Stargardt disease and geographic atrophy with so far encouraging results that allow to continue this route of research. Patients therefore call on Governments, politicians and society to do all their best to give every person in Europe affected by a retinal degeneration access to

- early and reliable diagnosis including genotyping
- genetic counseling if desired by the patient or its family
- treatment options where available
- rehabilitation and auxiliary aids

In order to speed up the development of treatment options for all the untreatable causes of blindness, we ask governments and society to

- speed up research by attributing funds especially to vision research
- attribute funds to find the missing genes (only 50 % of the genes causing inherited retinal degenerative diseases are known)
- allocate funds to explore new treatment options and translational research in vision

With these special efforts by all, researchers, patients and society, we will hopefully see the day when blindness due to complex eye diseases can be avoided.

Work package IX: Development, implementation and management of web-based portal

The „Vision Research Gateway“ is a web based portal, having as major purpose to be in service for the European vision research community. The idea to develop such an instrument emerged from the urgent necessity to give this community a sharper visibility, a consolidated profile and at the same time to underline the importance of its work and activities in science and within the society. The urgency to act was also reinforced by the peculiarity of the European research landscape: this landscape is mostly characterised by a strong fragmentation and this is particularly true for the field of vision research. Trying to gain a greater insight into the ophthalmologic organisations across Europe, we quickly realised that the actual situation resembles much more a not-assembled puzzle than a detailed geographic map: it is true, that each European country has, at least, one national ophthalmologic society, but many of them have no internet presence and a good portion of

the rest, having a website is only readable and reachable in the respective national language. Consequently, many of them are very difficult to be contacted without a time intense investigation. After this experience, our conclusion is, that most of all national organisations are still acting and thinking in a local level, or, at least, their display window on to their activities is only visible and accessible for a local public. This fragmentation is not only due to historical, cultural facts and language barriers, but also due to strong local interests and to national funding systems. We are of the opinion, that an important factor to lower international fragmentation will be the joint active request, or activation, of funds at a European level. This is not new that the success and acceptance of any project depends on its ability to bring its results to the surface, letting the right people know how these results have been achieved and how these results would have a positive impact on science and society. The portal wants to become the “megaphone” of the European vision research “chorus”, raising the awareness for this field. It wants to disseminate in a highly effective way and in real time dimensions information to stakeholders and to the wider public about its activities. Broadening the network, using the adequate communication strategy and language will doubtlessly enhance the acceptance, but, moreover offering a common platform, the transparency will be ameliorated, reducing the risk of unnecessary duplication of work. The problem for many societies, organisations or researcher groups, however is not mainly the lack of resource to communicate effectively their activities, but there is rather a lack of real expertise in presenting the information appropriately, therefore a professionally developed and managed web based instrument is nowadays not only necessary, but indisputably one of the best ways to help to meet the aforementioned challenges, reaching a wider public compound by scientists, journalists, young students, politicians and decision makers. The portal wants to offer panoply of features and functionalities, tailored to suit the needs and requests of the European vision research community. Following features, after a standard registration of the user, will be available to everybody. The European Union Research Programme, supporting the idea of the „EuroVisionNet“ portal offers the European vision research community a unique opportunity to increase its acceptance and its visibility, to consolidate its profile and to win recognition as well in the scientific community as also in the society and policy. Researchers and their researchers groups, institutes and organisations, involved in this field have for the first time in Europe a virtual space to come together, to discuss and to be professionally represented. This the place to be, and we should not miss this incomparable chance, because if we do not use it now, we will lose it, losing with this, a mighty tool of dissemination for gaining political and scientific awareness.

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