

# 2012-2013: A Year in Review

## Macula Vision Research Foundation Annual Report

*This information represents our fiscal year October 1, 2012 – September 30, 2013 and our 15<sup>th</sup> year of operation.*



### **Mission**

The Macula Vision Research Foundation (MVRF) is a 501 (c)(3) organization dedicated to finding a cure for macular degeneration and other retinal diseases. To reach this goal, MVRF funds groundbreaking research projects conducted by the world's top scientists with the hope of improving the lives of millions of people affected by visual impairment. What makes MVRF unique is that 100% of every dollar donated goes directly to research. All administrative and fundraising expenses are underwritten by the Karen and Herb Lotman Foundation, allowing MVRF to allocate all donations towards finding a cure. Along with funding research, MVRF also provides education and outreach to those with visual impairments through our SupportSight<sup>SM</sup> seminars and newsletter.

### **Our MVRF Team**

Dawn Prall George  
*Executive Director*

Amy L. Singer  
*Director of Development*

Nikki Grossman  
*Marketing & Communications Coordinator*

Lynn Rinaldi  
*Outreach & Education Coordinator*

### **Board of Directors**

Herbert Lotman  
Karen Lotman  
Shelly Fisher  
Jeffrey Lotman  
Robert S. Molday, PhD  
Colin J. Barnstable, DPhil  
Dean Bok, PhD  
William W. Hauswirth, PhD  
Roderick R. McInnes, MD, PhD  
Philip J. Rosenfeld, MD, PhD

## **International Scientific Advisory Board**

Robert Molday, PhD

*Director, Center for Macular Research  
University of British Columbia, Vancouver, BC*

Colin Barnstable, PhD

*Professor and Chair, Department of Neural and Behavioral Sciences  
Pennsylvania State University College of Medicine, Hershey, PA*

Dean Bok, PhD

*Distinguished Professor of Neurobiology  
Dolly Green Professor of Ophthalmology  
University of California, Los Angeles*

William Hauswirth, PhD

*Professor, Department of Molecular Genetics  
Rybaczki-Bullard Professor, Department of Ophthalmology  
College of Medicine, University of Florida, Gainesville, FL*

Roderick McInnes, MD, PhD

*Director, Lady Davis Research Institute, Jewish General Hospital  
McGill University, Montréal, Quebec*

Philip J. Rosenfeld, MD, PhD

*Professor of Ophthalmology, Bascom Palmer Eye Institute  
University of Miami Miller School of Medicine, Miami, FL'*

## **Academic & Institutional Partners**

Beckman Vision Center	Tufts University School of Medicine
Casey Eye Institute	UCL Institute of Child Health (London)
Columbia University	University of Arizona
Duke University Medical Center	University of California Santa Barbara
Eccles Institute of Human Genetics	University of California, Berkeley
Hadassah Hebrew University Medical Center	University of Florida
Harvard Medical School	University of Iowa
Harvard University	University of Iowa Hospitals and Clinics
Institute of Human Genetics	University of Kentucky
Johns Hopkins University School of Medicine	University of North Dakota
Jules Stein Eye Center	University of Pennsylvania
Jules Stein Eye Institute, UCLA	University of Pennsylvania School of Veterinary Medicine
Medical University Vienna	University of Southampton (UK)
Moran Eye Center	University of Utah
Neural Stem Cell Institute, Rensselaer, NY	University of Washington School of Medicine
Neuroscience Institute, Pisa, Italy	University of Wisconsin-Madison
Radboud University, Nijmegen, The Netherlands	W.K. Kellogg Eye Center
Scheie Eye Institute	Washington University School of Medicine
St. Jude Children's Research Hospital	Weill Medical College of Cornell University
The Cleveland Clinic	Western General Hospital Edinburgh
The Jackson Laboratory	Wilmer Eye Institute
The Johns Hopkins University	Yale University School of Medicine
The University of Alabama at Birmingham	

### **Celebrity Ambassadors**

*These stars are shining light on our important mission...*

Buzz Aldrin  
Edward Asner  
Angela Bassett  
Shari Belafonte  
Richard Dreyfuss  
Hector Elizondo  
David James Elliott  
Brad Garrett  
Hal Holbrook  
Penny Marshall  
The Reverend Dr. Della Reese Lett  
Nancy Sinatra  
Cheryl Tiegs  
Hunter Tylo  
Al Unser, Jr.  
Christopher Walken

### **Highlights & Accomplishments**

- Hired a new Executive Director
- Implemented a new 3-year strategic plan
  - Improved communications strategy for web, proposals and social media
  - Executed a new social marketing strategy and increased Facebook fans by 15%
  - Launched a newly designed website, [www.MVRF.org](http://www.MVRF.org)
- Convened the 11<sup>th</sup> Scientific Conference in Chicago, IL on October 18-21<sup>st</sup>, 2012
  - 23 world-renowned vision scientists discussed recent progress in therapeutic strategies for treatment of macular degeneration and related inherited blinding diseases
- Increased grant cycle funding amount by 25% to \$100,000/year for 3 years
- Awarded 4 new grants
- Distributed 3 SupportSight<sup>SM</sup>NEWS publications with improved content and increased readership by 10% - total circulation of 25,000
- Partnered with The Middle Atlantic Blind Golf Association for their 2013 Invitational Golf Tournament which raised more than \$50,000 in total

## Currently Funded Grants

### **2013-2014 Grant Recipients:**

Frans Cremers, PhD

Nijmegen Medical Center, Radboud University

The Netherlands

Name of Study: Transcriptome Analysis of iPSC-Derived Retinal Cells of Patients with Inherited Retinal Dystrophies

Roxana Radu, MD

Jules Stein Eye Institute, UCLA

Los Angeles, California

Name of Study: Gene-Therapy to Prevent Visual Loss in Macular Degenerations by Increasing Expression of Complement Negative-Regulatory Proteins in the RPE

Enrica Strettoi, PhD

Institute of Neuroscience, Italian National Research Council

Pisa, Italy

Name of Study: Sphingolipid Ceramide Signaling In Retinal Degeneration: In Vivo Targeting

Sally Temple, PhD

Neural Stem Cell Institute, Regenerative Research Foundation

Rensselaer, New York

Name of Study: Reprogramming the Human Retinal Pigment Epithelial Stem Cells (RPESCs) into Photoreceptor Cells

### **2<sup>nd</sup> & 3<sup>rd</sup> Year Grant Recipients:**

Samuel Jacobson, MD, PhD and William Hauswirth, PhD

Scheie Eye Institute, University of Florida

Name of Study: Treatments for Inherited Macular Degenerations, Specifically Blue Cone Monochromacy

Anneke den Hollander, PhD

Radboud Univ. Nijmegen Medical Center, Department of Ophthalmology

Name of Study: Genetic and Immunological Causes of Central Serous Retinopathy

Gustavo Aguirre, VMD, PhD

University of Pennsylvania School of Veterinary Medicine

Name of Study: Gene Replacement Therapy in Bestrophin 1 Model: Implications for Recessive and Dominant Human BEST1-Disorders

Wolfgang Drexler, PhD

Medical University Vienna

Name of Study: Comprehensive Choroidal and Cellular Resolution Retinal OCT of Macular Degenerations

Sheila Nirenberg, PhD

Weill Medical College of Cornell University

Name of Study: A Retinal Prosthetic for the Treatment of Advanced Stage Macular Degeneration: A Device with the Potential to Restore Normal or Near-normal Vision

Austin Roorda, PhD

University of California, Berkeley

Name of Study: Improved Structure/Function Measures in dry-AMD

## **Financial Report**

For year ended September 30, 2012

- Total income in the past fiscal year \$3.8 MM
- Total program expenses \$3.1 MM
- Total fund raising expenses \$ 221,607
- Total administrative expenses \$ 224,568
- End of year assets \$ (156,888)
- IRS form 990 (on website)

### **Looking Forward...**

- Our 12<sup>th</sup> Scientific Conference will be held on March 21-23, 2014 in Atlanta, Georgia
- We will be holding a SupportSight<sup>SM</sup> Seminar on October 22, 2013 in Cleveland, Ohio
- Upcoming SupportSight<sup>SM</sup> Seminars (dates TBD):
  - Phoenix, Arizona - Winter 2014
  - Atlanta, Georgia - Spring 2014
  - Philadelphia Region - Summer 2014
  - Austin, Texas - Summer 2014