



So much yet to see..
Please, help.

Blindness steals more than vision..

It robs our children, parents and family of
a lifetime of hopes and dreams.

With your support, RP International stands
Between the darkness and those we love,
by funding these critically needed programs.

Retinitis Pigmentosa International ~ Annual Report

Giving the Gift of Sight

The first book written on RP, was funded by RP International for \$75,000. There was no physical book in New York Medical schools at that time. The Visually Handicapped School of the Valley received much of its funding for years at UCLA and now receives at least \$75,000 a year from RPI.

Night Vision Aids

Devices for the blind, the night vision scope, has been given to a young person each year at the Vision Award dinner - at least thirty-seven of them to date. Two night vision aids - brand new technology - have been given to two centers right here in Los Angeles - The Center for the Partially Sighted and the Jules Stein Eye Institute.

The Eisenhower Medical Center Hospital in Rancho Mirage was given a specially designed piece of equipment for detection of RP patients in the name of Bob Hope - valued at \$35,000. The same device was given to the Desert Hospital in honor of Barbara and Frank Sinatra. There was no such equipment in any hospitals at that time.

Research Conferences

Doctors conferences have been held ever other year for 35 years in Los Angeles since RP began working with the transplant physicians, Dr. Manuel del Cerro of Rochester University, Dr. Peter Gouras of Columbia University, Dr. James Turner of North Carolina and Dr. Martin S. Silverman of Washington University in St. Louis. A special three-day Le Belage Conference was held in 1993 when physicians met for three days and at the end of each day answered roundtable questions from patients and their families.

No staff time other than the two man staff at RP International was a cost of the project. However, doctors were provided with airfare, accommodations and meals (expenses were covered from the research fund). RPI funds these important conferences which are not only effective in research but also the publicity and awareness generated is priceless and bring attention to RP International and our goals.

Todd Cantrell went to Russia for the first encad treatment and RPI brought him to Los Angeles for further testing and to the Center for the Partially Sighted. Photos and video coverage of all of this was managed by donations clearly committed by the Advisory Committee of RP International.

Trips to Germany and Cuba by our producer/board member brought back much needed information on the surgery in Cuba and the drug in Germany. Videos of the medical procedures in Havana by Dr. Orfilio Pelaez was obtained plus research records from Lubeck University by Professor Doctor E.S. El-Hifnawi. There were several additional trips to visit patients at the Irvine Medical Center and doctors conferences were also held there.

TheatreVision

Three to five million dollars was spent delivering the technology for the first-ever synchronized description of movies for the blind. The first movie in a theatre for the blind, *Forrest Gump* shown in 1994. The National Institute for the Deaf took 25 years to accomplish nearly the same difficulties at many times the cost.

Financials

Helen Harris and family started and funded the beginnings of RP International and still today give all that they have to bring the disease to a final cure. In the early days, it was just phone and pencils and paper, notebooks, three by five cards, scotch tape, paper clips and all of the other paraphernalia required to begin an operation that was determined to find a cure for retinitis pigmentosa. Helen sold one of her favorite paintings, only to buy the air time for the first RP telethon which aired in 1980 on KCAL, hosted by volunteers Bob Hope, Danny Kaye, Carol Lawrence, Vin Scully, Tommy Lasorda and others. None knew that the funding came from the meager salary according to today's standards of Bob Harris' salary and Helen's penny pinching shopping. The family did without a lot of things: no new cars, no trips, no boat, all of the dreams of Helen Harris were held away at least temporarily. Thirty-three years until the day would come.

When the cure is found today, she admits that it was worth it, and she would sell the best years of her eyes, her art collection, her paintings, if it would result in the millions needed now to meet the challenge and offer restored eyesight to all, a difficult task for Harris, since she believes that she could not ever paint them again...still?

Seventeen million dollars went to the National Eye Institute after Helen Harris proposed it to the Appropriations Committee in her visit in 1990. Two further visits sent more money directly to universities around the country: Harvard, Columbia, the University of Washington, UCLA, the Estelle Doheny Eye Foundation at USC and more.

Three hundred million dollars was later sent directly to universities as a result directly from the work of Helen Harris. The donor was honored, impressed and donated the money directly after being honored at the RP Vision Awards. Harris and RPI were just happy to see the recognition and funds go to research. Sadly, none of it at first went to the now proven cell transplant and Harris is on a mission to find out how much went to regular RP research and how much to RP International's ongoing exhausting schedules. Thousands of families received more than 25 million dollars in brochures every five years. Now since DVD is here, the establishment is underway to have a talking understandable presentation to those who need the most: the stricken ones and their families.

Three million dollars has been used campaigning the senate, ophthalmologists, and state governors in every state to get behind RP and now 50 governors proudly send out their own vision of Christmas through the offices of Helen Harris and RP International because of her own patient communications.

Future plans for funding for RP International:

The School for Blind Adults is now located in the San Fernando Valley and needs \$75,000 to \$100,000 annually to fund. However, at this time, RP International is actively seeking funds for a building of its own for the blind and for assistive disability persons with special needs. Realtors are looking for appropriate property now, and of course grants and donations are being requested.

The first book was published on retinitis pigmentosa by RP. This book needs to be updated, additional copies need to be printed; funds are needed to gather information, pay the writers, develop color photos of a never-seen-before disease and many other resulting conditions, including loss of life. Families and counselors took and will take millions to help the blind live through the devastating affects of RP and macular degeneration.

Building centers and programs for daily needs of the blind are intricate and expensive. Talking clocks, the night vision aid, the chair lifts, night vision goggles, simple white canes, talking computers, their talking equipment are estimated in the seven to ten million dollar cost.

Out-patient guide dogs are underway, and this has never before been attempted.

RP International is entering a capital campaign study for its feasibility. It is very badly needed, and RPI believes that more and more people would use the guide dog service.

What RPI is doing now

As the days go by - the ever increasing emails, telephone calls, letters and inquiries from schools, doctors and every facility of learning, you can imagine how it inundates RP International.

- Libraries in every city want material, brochures, videos and our TheatreVision tapes of described movies.
- Every university has adult students who in the midst of career choosing, learn they have a form of degenerative eye disease.
- Some have sight loss coming on and hearing loss at the same time, called Usher's Syndrome, leaving a healthy and wonderful child or adult terrified at the thought of living in a dark and silent world. They contact us through the relay operator or TTD equipment.

Others, thousands of others, want information on how to prevent degenerative eye disease. If a family generation has shown signs of its hereditary forecast, families often have more than one member diagnosed and the requests and time that it takes for all of us to spend with this is nearly unaccountable. Yet, we cannot leave patients alone without any sign of hope, so we offer the best in information, knowing that RP International is like an ever-searching organization for that cure or treatment. It is a great relief for those that cannot do it for themselves.

Today, we manage the VHAV School for the Blind as one of our senior projects in Van Nuys. Adults can come and meet others, learn Braille, macramé, sculpting, history, mobility training, Spanish, current events, TheatreVision movies and ceramics. Even bowling takes place each week with bowlers as young as ninety still making their game and without sight. It's amazing.

Mission for Our Future

Now that the retinal cell transplant, stem cell transplant and adult transplant have been recognized as a viable way to halt and reverse many diseases, RP International has been vindicated you might say, since we were the first to recognize the cell transplant taken from a patient's own eyes in the mid-eighties. Lorine sees the cell transplant as her saving grace. Blind, and then able to see again, and RP International was there to witness it.

The mission that resulted from that and many medical meetings is this:

That retinal cells one day would replace dying cells and from one's own eyes or donor eyes causing restoration of eyesight. Because of the inability to get funding for furthering the project, RP International and all of its medical board suffered the loss with a great deal of dismay.

One physician said to me personally, **“Helen, I've been told that if I work with you and your retinal cell transplant work, my other grants will be taken away and I cannot afford it. So, I wear a heavy heart knowing you are right on the path and you have put together the finest group of physicians ever to make this dream a reality and a successful sight restorer. All you can do is wait until the world catches up.”**

Five physicians met with me regularly. Discussions and conferences were held and will be held again now that the position has changed and the possibilities have opened for a transplant to restore sight, make a heart beat again and a child walk once more.

We are now preparing a seminar for fall 2006 and the direction to go now that the first child has been approved to receive the stem cell transplant into his brain. The disease is Batten's and six year old Daniel will be first (and soon his parents hope).

In a wheelchair and with failing or nearly gone vision, Daniel smiles love everywhere he goes, and even through the grueling tests he managed to have all the staff at the hospital cherish meeting him. Tearfully they said goodbye hoping the next time they see him he will be walking alone, seeing and able to do all that a six year old should do. The cell transplant from stem cells will be done, with Daniel first in early summer.

The sister who gladly gave her own brother her stem cells, adult stem cells from her own eyes is another story and a happy one. He was blind for twenty two years and since then has seen nothing. When the cell transplant donated by his sister's adult stem cells to his eyes, his sight returned, and he sees.

Our goal is to equip first a printing situation of pamphlets in audio, Braille and large print to tell so many others how much is being done. The most for this will be a million dollars in the first run.

Mobility training videos are to be developed and when the VHAV on-site trainer is not around, hopefully the video, described in TheatreVision and music will supplement the student learning to travel without sight while the search for the cure goes on.

Braille books are needed in the poorer parts of the United States and have been often mailed out and then returned to the adult blind center locally for use by others.

In the center we have had for more than twenty years a model property. We intend to suggest to every department of rehabilitation in each city to begin discovering a way to establish these centers citywide and statewide. They are the only light of hope in the long, dark days of a blind person. Seniors especially can have all kinds of activities planned and executed with sighted guides if there is proper funding. Hospitals can be places of gathering for conversation, education and use of mobility guides which are presently not now covered under any insurance plan. For instance, if you went to the hospital with a broken leg and needed crutches, you would be able get them under insurance or medicare plans at least partially paid for if not entirely. Yet, a blind patient cannot move from the bed in any direction without grave danger and without personal help and mobility training. These costs would be repaid in less accidents and quicker recoveries.

The Center for Regeneration of Adult Stem Cell and The Stem Cell Institute will be established at a cost of 10.2 million dollars to bring information and guidance to those needing this application for their eyes. Other diseases are well-covered under all plans for this new innovative treatment, yet blindness and degenerative diseases are not. A study group will be put together, made up of patients, corporate leaders, doctors and technology experts along with bio-medical and surgeons for an all encompassing advisory committee which will be active, meeting weekly and performing monthly. Each member will be evaluated monthly for their participation and real interest in the committee to judge their continued involvement.

Facilities will be necessary for testing on animal models and then quickly to get patients into voluntary safe programs that will restore sight as quickly as possible, following the model of the *Miracle Worker* television show written on a true case history where this actually happened.

Progress will be discussed and decisions made as to plan a great successful stem cell, adult stem cell program, including retinal stem cell, success for ending blindness.

The goal of 10.2 million is expected to cover an eighteen month period at this time.

As this all new ground, we will make changes as necessary.



Helen Harris
President of RP International
Retinal Regeneration Stem Cell/Adult Stem Cell Institute™

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INDEPENDENT AUDITOR'S REPORT

To the Board of Trustees of
Retinitis Pigmentosa International Society for
Degenerative Eye Diseases and Related Disorders, Inc.

We have audited the accompanying statements of financial position of Retinitis Pigmentosa International Society for Degenerative Eye Diseases and Related Disorders, Inc. (a nonprofit organization) as of June 30, 2011 and 2010, and the related statements of activities, cash flows and functional expenses for the year ended June 30, 2011. These financial statements are the responsibility of the Organization's management. Our responsibility is to express an opinion on these financial statements based on our audit.

We conducted our audit in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. An audit includes examining, on a test basis, evidence supporting the amounts and disclosures in the financial statements. An audit also includes assessing the accounting principles used and significant estimates made by management, as well as evaluating the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of Retinitis Pigmentosa International Society for Degenerative Eye Diseases and Related Disorders, Inc. as of June 30, 2011 and 2010, and the changes in its net assets and its cash flows for the year ended June 30, 2011, in conformity with accounting principles generally accepted in the United States of America.

Willing & Moser, An Accountancy Corporation

Willing Accountancy Corporation

September 12, 2012



RP International

Mission and Objectives



In the United States today, because 90% or more of every dollar raised goes to program services, it places the charity among the most efficient fundraising organizations. We thank the countless professionals and volunteers who donate so much of their time, talent and resources for making this possible! To date, RPI and its committed supporters, have raised or directly caused the donation of 350 million dollars to major medical facilities. Provided free services to 250,000 “National Crisis Line Callers” and brought the miracle of restoring vision from a distant hope, to the reality of clinical and experimental trials today.

I Medical Research:

a. **Retinal Cell Transplantation**

- a. Dr. Gholam Peyman, LSU Lions Eye Center
- b. Jules Stein Eye Institute, UCLA
- c. Estelle Doheny Eye Institute, USC
- d. Complete list & videos available at VisionAwards.org,
RPInternational.org, EyesOfChristmas.org

b. **Bio-Medical Computer Implants**

(recently featured for a the second time on NBC Dateline, 20/20 and 60 Minutes)

c. **Pharmacological Interventions**

- d. **Medical Seminars and Research Symposiums** (Keck Center, Hilton Hotel, American Academy of Ophthalmology Annual Conference)

II Patient Services:

a. **Accessibility**

1. TheatreVision (Television, Movies & Live Events)
2. Talking Technologies for distance Learning K1-College
3. The “Senior Center” serving 150 low vision patients
4. National 800 crisis line counseling. Helping over 250,000 callers to date free of charge
5. Free Patient Survival Kits, mailed over 300,000.
6. Night Lighter Newsletter published 4 times per year
7. California State University Northridge, CSUN future training site for “TheatreVision”

III Public Awareness & Advocacy:

- a. **National Eye Institute (NEI)** advocacy program to successfully increase their annual funding by 17%

- b. **National Television, Radio, Print and Public Awareness Campaigns.**

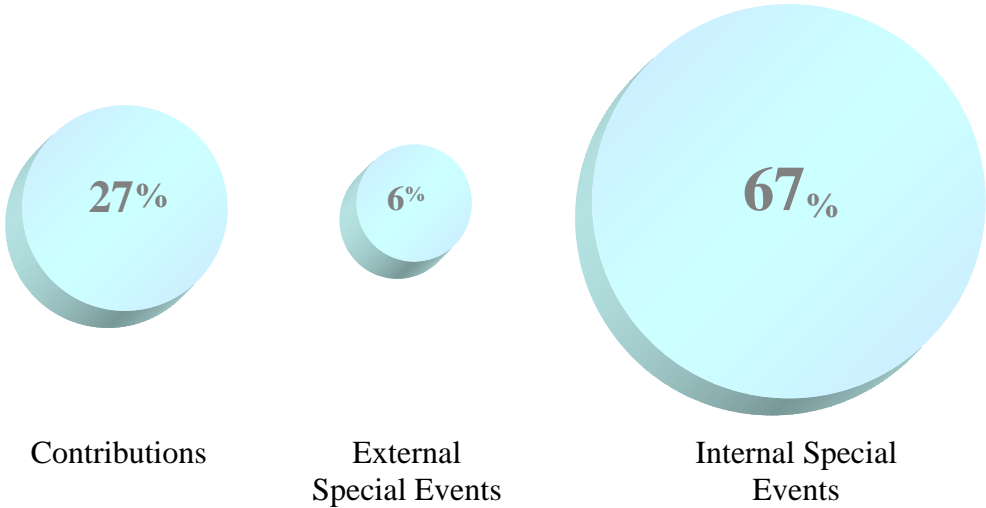
1. 40th Annual Vision Awards
2. The “Hope in Sight Telethon” hosted by Bob Hope
3. The “Eyes of Christmas” national television special
4. Blind Olympic with TheatreVision Movies
5. Variety of Marathons, Golf Tournament and Regional Fundraisers
6. Over 1,200 Television, Radio and Print feature stories.

Retinitis Pigmentosa International Society for Degenerative Eye Diseases and Related Disorders is a 501(c3) tax exempt Non-Profit Corporation meeting or exceeding all Federal, State and City of Los Angeles Department of Social Service Regulations.

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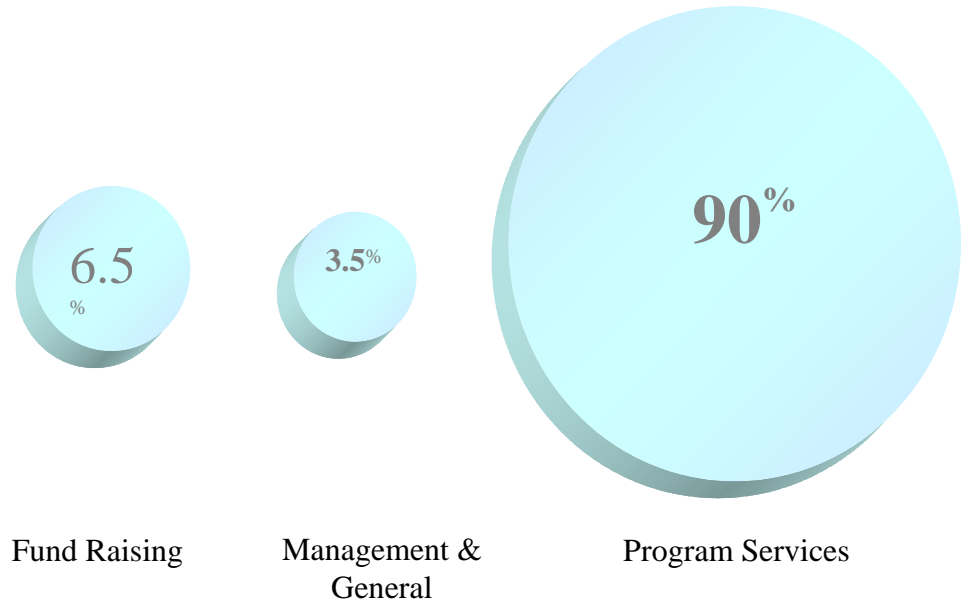
Managing Our Funds

Sources of Funding



Functional Expenses

As a percentage of total support and revenue



50,000 "Adam's" call each year. With your help, we're there to answer the call...



In the past two years alone on the Vision Awards stage, we were introduced to three miracles. First, two young people joined us – the sister had donated her own adult stem cells to her brother who had not seen in twenty-two years, he can now see his wife, three children, the ocean and the sunrise. Second, a new drug was introduced that is now available to help alleviate the effects of macular degeneration. A child in a fight for his life against Batten Disease, a neurological disorder which includes degenerative blindness, loss of motor function and eventually death, made medical history after receiving the first neural cell transplant in the world. That was over a year and a half ago and I'm proud to say he is still alive and well. Today, he is not only happily attending school, but serves as an official AAA little league batboy.

Imagine we've had the reversal of blindness in our lifetime. **It's true.** Several of our clinical trials have restored vision to previously blind children and seniors. Without the funding the Vision Awards provides, these miracles would never have been possible. We truly believe we have found a cure! Now we only need to fund it!

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Blindness steals more than vision..

It robs our children, parents and family of
a lifetime of hopes and dreams.

With your support, RP International stands between
the darkness and those we love, by funding
these critically needed programs in;



Major Medical Research Centers and Universities;
Congressional Testimony and White House Meeting
with President George H.W. Bush

RPInternational.org
Fighting Blindness for 33 Years



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RP International

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RP International.org * VisionAwards.org * EyesOfChristmas.org

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