ANNUAL REPORT 2013

FOUNDATION
FIGHTING
BLINDNESS

Momentum

ANNUAL REPORT 2013


**P=mv.** That’s the mathematical equation for momentum. The “p” is for Greek and Latin words indicating movement, the “m” and “v” mass and velocity. So, momentum is equal to mass x velocity. In other words, the bigger you are and the faster you’re moving, the more momentum you gain. Unless, that is, something slows you down.

Now in its 42nd year, the Foundation Fighting Blindness is a national organization with roughly 50 chapters and more than 130,000 active donors and volunteers across the country. The Foundation’s reach is global, and it has a revenue history of almost $550 million. That’s quite a bit of mass. As for velocity, this past decade’s technological and scientific advancements have helped us accelerate drug, gene and cell-based therapies into pre-clinical and clinical trials that were unimaginable at the turn of the 21st century.

Fiscal year 2013 continued to drive that momentum. For the second year in a row, we invested more than $20 million into research and public health education projects while growing our fundraising and membership programs and launching a major-gifts campaign. (More on this to follow.)

This year’s progress wouldn’t have been possible were it not for growing momentum on a variety of fronts. Gene identification as well as drug and gene therapy development are moving at breakneck paces, compared to 10 years ago. Just as impressive is recent progress in a field the Foundation’s been behind since its inception: stem cell research. In “Beating the Curve” (pg. 2), Dr. David Gamm, a Foundation-funded clinician-researcher, explains why cell-based therapies are so promising and how a project he’s leading could restore sight to those affected by a variety of retinal diseases.

Our grassroots efforts — chapter and dinner events, 5K VisionWalks and other activities — continue to fuel fundraising and awareness-building nationwide. One reason is that, in each FFB chapter, take-charge
members are inspiring others to up their games. “It’s Never Too Late” (pg. 4) spotlights Martha Steele, a Boston-area resident whose work in 2013 (and previous years) with the local chapter and VisionWalk exemplifies optimal grassroots advocacy.

There’s much more to share from fiscal year 2013, as you’ll see. But before you dive into this report’s pages, we want to offer you a glimpse of the Foundation’s future — Envision 20/20: The Campaign to End Blindness, a campaign to ensure we continue to grow our momentum. Launched this year, the campaign aims to raise $300 million by 2020.

As FFB’s first initiative of this magnitude, The Campaign to End Blindness is truly a means to an end. Thanks to the sustained momentum built by you, our dedicated donors and volunteers, now is the time to end blindness. We look forward to updating you on this campaign in the coming months and years.

Until then, we thank you for an extraordinary year and invite you to dive into the details of this report.

Sincerely,

Chairman Gordon Gund (left) and CEO Bill Schmidt

Gordon Gund
Chairman and Co-Founder

William T. Schmidt
Chief Executive Officer
“When I think of stem-cell-based therapies and technology, the word ‘momentum’ is paramount. In many ways, we’ve beaten the curve to this point.”

That’s Dr. David Gamm, a clinician-researcher whose career began not long after Dr. James Thomson, a colleague at the University of Wisconsin, discovered a way to grow human embryonic stem cells — cells that can be coaxed into becoming any kind of human tissue — in 1998. Several years later, Dr. Thomson derived what are called induced pluripotent stem cells, or iPS cells, from adult blood. Now, with Foundation funding, he, Dr. Gamm and others are hard at work turning iPS cells into potentially vision-restoring retinal cells.

There are two reasons for this turn of events. “One, scientific technology has grown exponentially, with sophisticated techniques and concepts evolving,” Dr. Gamm, M.D., Ph.D, explains. “And, two, very talented individuals are entering the field.” The Foundation, he adds, is a leader in facilitating stem cell research targeting retinal diseases. “That’s part of its history — identifying promising areas and getting in right off the bat, so it can initiate and maintain momentum.”

In 2013, the Foundation awarded Dr. Gamm and his team $900,000 to develop a “retinal patch,” a two-layered set of stem cells designed to replace two types of cells damaged by various retinal diseases — photoreceptors and retinal pigment epithelial (RPE) cells. Says Dr. Gamm: “The analogy I like to use is, if your car doesn’t run and you don’t have pistons or a carburetor, putting just a carburetor or pistons back in isn’t going to get it to run. You need both.”

Fixing a retina, however, isn’t as simple. In stem cell research, there are three broad areas of momentum at present, according to Dr. Gamm: cell manufacture, cell installation and therapy evaluation. The first is farthest along, with RPE, in particular, “a relatively easy cell type to grow,” he says. But mixing RPE cells...
with photoreceptors, then installing them in the retina “and having them survive, make the right connections and continue to function — a lot of work needs to be done.” And evaluation comes into play only after installation.

Thankfully, many labs worldwide are working hard on the installation challenge, with each one learning from the others. Dr. Gamm expects major advancements within the next 10 years.

Another notable area of stem cell research receiving Foundation funding is disease modeling. Because iPSC cells are derived from skin or blood, “samples from people affected by retinal diseases are sent to us,” Dr. Gamm explains. iPSC cells are then created, directed to turn into retinal cells and placed in a dish, where they’re tested with various treatments. Only those that work will be shuttled toward clinical trials. “So instead of just shooting from the hip,” Dr. Gamm says, “we can customize therapies based on the actual dysfunctions that are going on at the cellular level.”

With so many stem cell options, Dr. Gamm is reminded of the Foundation’s “diversified portfolio” approach to fighting blindness — one featuring not just stem cell, but gene and drug therapies too. “The Foundation,” he says, “does a great job applying the right amount of emphasis to different fields and identifying new ones.”

“The Foundation does a great job applying the right amount of emphasis to different fields and identifying new ones,” Dr. Gamm says.
Martha Steele is a scientist, a trained toxicologist whose job as deputy director for the Bureau of Environmental Health at the Massachusetts Department of Public Health has her overseeing everything from food-poisoning cases to environmental investigations of nuclear power plants.

The 61-year-old also has Usher syndrome, which causes hearing and vision loss. So it took scientific evidence — presented at a Vision Seminar in Boston five years ago — to convince her the time had come to adopt the Foundation’s mission as her own.

And, indeed, she has. “Martha has reinvigorated the Boston region by focusing not just on the city but its suburbs as well,” says Maria Costa, FFB’s director of development for the northeast region. “She’s hosted a chapter speaker series presentation and developed a new networking group in Arlington. It’s a great example of what’s happening nationwide — people affected by retinal diseases taking charge and encouraging others to either become involved or get more involved.”

Martha admits that, before the seminar, “I hadn’t been following the research. But there was clearly a lot of excitement from the researchers talking about gene, drug and stem cell therapies and upcoming clinical trials. So that led me, initially, to get involved with the Foundation through VisionWalk.”

This year, she chaired the Boston VisionWalk for the fourth year in a row. And her team, Strides for Eagle Eyes, brought its grand total, over five walks, to $120,000. As the Boston Chapter’s president, she has also reinstituted the region’s speaker series — meetings featuring local research and low vision specialists. She began in February with a presentation by Dr. Eric Pierce, who is associate director of the Foundation-funded Berman-Gund Lab for the Study of Retinal Degenerations at Harvard University. “That was on a week night, and it was jammed, with more than 100 people,” Martha recalls.

Other speaking events are scheduled for the fall and winter, as are monthly networking group meetings.
at a local public library. “We had our first one in July,” Martha says. “It’s a way to reach out to those affected, and keep them informed about research and support them. We meet if it’s just one person or 16. I want people to know these group meetings won’t go away.”

So why the momentum now, even though Martha, who began wearing hearing aids at age 5, was diagnosed with Usher syndrome 30-odd years ago? The answer, in part, is technology. Over the past several years, Martha’s vision has deteriorated considerably, preventing her from lip-reading, once her principal means of “hearing.” A few years ago, however, Cochlear implants changed all that, as did a recent stint at The Carroll Center for the Blind, where she trained in state-of-the-art visual strategies.

Martha’s also been energized by the response to her annual VisionWalk appeals. Working with a list of roughly 500 connections, ranging from childhood friends to people with whom she does business, she sends out a letter sharing the vision loss she experienced over the previous year. “The bottom line,” she says, “is people are donating I think not so much to FFB as they are to support me.”

But it’s the Foundation’s work that motivates Martha, who was recently elected an FFB National Trustee. “I’m impressed with the breadth of research projects in clinical trials right now,” she says. “I don’t think anything big will happen next year or the year after. But within the next decade, it will.”
It's been a banner year for the Foundation and retinal research, so highlighting the successes is a real challenge. But seeing as we’re reviewing fiscal year 2013, here are the Foundation’s top 13 milestones in research, fundraising and public awareness.

Research

1. First "bionic retina" becomes available
   The Food and Drug Administration granted market approval for the Argus II retinal prosthesis, the first device of its kind available in the U.S. that can restore some vision to people blind from advanced retinitis pigmentosa.

2. Gene therapy for LCA closer to FDA approval
   The landmark gene therapy study that restored significant vision in patients with Leber congenital amaurosis (LCA) has advanced to a Phase III clinical trial — one step closer to FDA market approval. In addition, more than 150 people have received gene therapy in studies underway for retinitis pigmentosa, choroideremia, Stargardt disease, Usher syndrome and macular degeneration.

3. New Stargardt disease study launched
   The Foundation’s Clinical Research Institute started a natural history study of people affected by Stargardt disease, called ProgSTAR, to help researchers gain a better understanding of the condition and to develop optimal outcome measures for forthcoming clinical trials.

4. Promise in stem cell research
   The first-ever stem cell clinical trial targeting retinitis pigmentosa is poised to begin in 2014, aiming to rescue photoreceptor cells and preserve vision.

5. Seed money blooms
   Thanks to early Foundation support, two start-up biotech companies developing gene therapies for retinal diseases attracted nearly $40 million dollars each in venture capital funding to help move the treatments forward. Applied Genetic Technologies Corporation (AGTC) is targeting achromatopsia and X-linked retinoschisis, and GenSight Biologics is targeting retinitis pigmentosa.
**Fundraising**

**6 A powerful partnership**
The Foundation launched a national campaign with Walmart called Save Your Vision Month, engaging the retailer’s associates in volunteerism that led to $1.2 million in grant money from the Walmart Foundation.

**Outreach and Awareness**

**8 Footsteps with a purpose**
VisionWalk, the Foundation’s signature 5K fundraising program, surpassed the $28 million mark, with more than 50 annual walkathons engaging 100,000 people in the fight against blindness to date, since 2006.

**9 Maximizing social buzz**
The Foundation’s social media presence expanded, with a Facebook following that grew by 6,000, to more than 17,000 fans. Twitter followers increased to more than 4,500, and the Eye on the Cure blog celebrated one year of compelling posts.

**10 A record-breaking conference**
More than 600 attendees converged at the Foundation’s national conference, VISIONS 2013, for four days of networking, informative sessions and volunteer leadership training.

**11 Power of the PSA**
Radio public service announcements (PSAs) raising awareness about the Foundation and age-related macular degeneration aired on more than 250 radio stations across the country. And print PSAs appeared in national publications, including The Wall Street Journal, AARP The Magazine, AARP Bulletin and Forbes magazine, reaching millions.

**12 Reaching patients in need**
More than 5,000 patients received free disease information from FFB. And nearly 1,500 people attended a Foundation Vision Seminar, hearing directly from top-notch retinal and low vision specialists about the latest research advances.

**13 Grassroots momentum**
The Foundation’s 47 chapters held countless fundraising, support, education and awareness events in their communities. Among the offerings were coffee socials, golf tournaments, wine tastings, speaker seminars and museum trips — a little something for everyone.
A Message from Our Treasurer

We are pleased to present the Statement of Activities and Financial Position for the Foundation Fighting Blindness’ fiscal year that ended June 30, 2013.

It was a very productive year, as the Foundation raised $44.7 million, its highest amount in revenues ever. This result continues the financial momentum we’ve built these past several years. It also brings the total earned by the Foundation since its inception in 1971 to almost $550 million.

Speaking of momentum, for the second consecutive year, the Foundation spent more than $20 million on research and public health education. We focused intently on awarding grants to a variety of promising projects, ranging from lab studies to pre-clinical and clinical trials.

Worth noting this year is a jump in special events revenues, from $8.7 million to $10.4 million, due largely to Walmart’s Save Your Vision Month program. The campaign, in which Walmart associates secured grants from the Walmart Foundation by participating in eye-health-awareness activities, garnered FFB $1.2 million.

Federal funding also increased, from $2 million to $4 million, with the launch of ProgSTAR, our Stargardt disease natural history study. The two-year study will involve 250 participants at nine sites worldwide, all focused on disease and vision loss progression so that researchers can best measure the outcomes of emerging therapies in clinical trials.

The launch of ProgSTAR, which promises long-term benefits, is just one example of the Foundation’s crucial work. Thanks to our support, researchers worldwide are ushering potential treatments and cures toward clinical trials, where their safety, efficacy and suitability for the marketplace will be determined.

The process of taking cures and treatments from the laboratory to the patient is extremely costly yet necessary. The closer we move therapies to the marketplace, the more we must continue to build our momentum for increasing revenues. A daunting task, yes, but one in which the Foundation — backed by dedicated staff members, volunteers and donors — has proven itself very capable. Eventually, these therapies will provide sight for millions of people worldwide.

Sincerely,

Haynes P. Lea
Treasurer
2013 Research Grants

In steadfast pursuit of its mission to find preventions, treatments and cures for the entire spectrum of inherited retinal degenerative diseases, the Foundation Fighting Blindness funds a diverse research portfolio that focuses on six priority areas: genetics, gene therapy, cellular mechanisms of diseases, clinical-structure and function relationships, novel medical therapy and regenerative medicine.

In fiscal year 2013, the Foundation and its Clinical Research Institute provided $17.5 million in support of 119 grants, including those for 13 collaborative research centers. The funded research projects are being conducted by 183 research investigators at 110 institutions, eye hospitals and universities within the United States and abroad, including laboratories in England, France, Germany, Italy, Israel, China and the Netherlands.

- Research Center grants totaled $4.8 million
- Individual Investigator Research grants totaled $7 million
- Alan Laties Career Development Program grants totaled $732,396
- FFB Clinical Research Institute clinical studies and grants totaled $5 million

For details on individual grants, including project descriptions, visit the financials section of the online version of this report at www.FightBlindness.org/AnnualReport. A complete copy of our audited financial statements is available upon request.

Statement of Activities 2013

REVENUE AND SUPPORT

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<td>Contributions</td>
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<td>Special events, net of direct</td>
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<td>Bequests</td>
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<td>Public Health Information</td>
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<td>Management</td>
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Change in unrestricted net assets: 2,646,000

Change in restricted net assets: 12,215,000

**Total change in net assets**: $14,861,000

Statement of Financial Position

ASSETS

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LIABILITIES

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NET ASSETS

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<td><strong>Total liabilities and net assets</strong></td>
<td><strong>$75,158,000</strong></td>
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THE FOUNDATION FIGHTING BLINDNESS

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