

TRANSFORMING LIVES

BOSTONSIGHT

ANNUAL REPORT 2017



BOSTON SIGHT

# B O S T O N S I G H T

“I’m not sure what would have happened (to me) if I had not come across PROSE treatment. When I go to see Dr. Carrasquillo each year for my comprehensive follow-up visit, she is equally amazed at the difference in my eyes. PROSE treatment is a real game changer.”

- Joseph Castelluci

*“I no longer spend my days rubbing my eyes or feeling constant burning. No one asks me what is wrong with my eyes, because they no longer look red. My light sensitivity is already better and I have 20/15 vision! It brings me to tears every time I think about how drastically my quality of life changed over just one week.”*

- Kelly Pucillo

“BostonSight gave me back my eyesight and my life as well. With the PROSE devices, I’m able to drive again, read, work on the computer, and do all the things most of us take for granted. Thank you from the bottom of my heart. Thanks to you ... now I can see!”

- Tom Topalian

*“At the age of two, I lost the vision in my right eye. Numerous surgeries and procedures couldn’t restore it for more than sixty years; until today. Like many patients who come from all over the world looking for hope and a last resort, I found remedy here. Today is the first day that I wear a prosthetic device developed by BostonSight that fully restored my vision. Many thanks to my doctors and their team!”*

- Benjamin Juárez



## VIEW FROM THE CHAIRMAN

David Rosenbloom, PhD

I'm very excited about the transformational change at BostonSight, not just from an organizational standpoint, but also in the ways we transform the lives of our patients.

As part of this transformation process, we have a great deal of work ahead of us. Many experts agree that poor vision is the world's number one unaddressed disability. In the United States alone, more than 4.24 million adults suffer from uncorrectable vision impairment and blindness. More than 2.16 million children and young adults have uncorrectable vision impairment. These statistics, coupled with the CDC's own definition, easily qualify vision loss and impairment as a significant public health concern.

Transformation at BostonSight is occurring to address a number of challenges. We must re-imagine and optimize our healthcare delivery protocols. We must grow our geographic footprint to reach more patients. We must expand the universe of eye conditions for which patients can be treated.

That's the beginning of the transformation – moving from a world in which our patients often experience limitations, pain and years of searching for effective treatment. We are looking to build a world filled with limitless possibilities.

We will innovate scleral technology to reduce treatment time. We will leverage telemedicine technology to efficiently train practitioners. We will strategically partner with organizations around the globe who can be hubs of scleral lens manufacturing. More of this vision is outlined on page 3.

I extend my thanks to our supporters for your mission-critical partnership. You are key to transforming the treatment of ocular surface disease – as are the BostonSight staff, who continue to push the boundaries of what is possible.



## FROM OUR PRESIDENT AND CEO

Gene Guselli, MBA

There are many things I'm proud of here at BostonSight; at the top of the list is our ability to offer treatment to the at-risk and underserved populations.

Currently there are 44 million uninsured U.S. citizens without access to eye care. As of 2016, there were also 46.7 million Americans living in poverty. Many of these individuals suffer with various forms of ocular surface disease, which can be treated by BostonSight scleral lenses. Historically, BostonSight has provided financial assistance to as many of these disadvantaged people as possible. The demand, however, far exceeds our current funding capabilities.

To date, BostonSight has treated over 10,000 patients who suffer with some kind of ocular impairment using our sight-saving PROSE scleral lens medical device. With an estimate of 45 million people worldwide who will have an ocular impairment by 2020, BostonSight's organizational and financial resources will be greatly tested in order to care for this expanding patient population.

To combat the world's number one unaddressed disability, I call upon patients and supporters to recognize the magnitude of the global vision impairment issue, and the critical role that BostonSight plays to address this challenge.

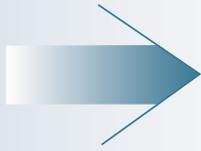
Our donors have an enormous impact. As a nonprofit eye healthcare organization, we depend upon your generosity to support the at-risk population. It allows us to not only address the immediate needs of this population, but also to support and participate in broader efforts to raise awareness of this critical public health issue. With that in mind, we hope to create a "Call-To-Action" initiative with the U.S. Department of Health and Human Services, to raise public awareness of eye disease and the at-risk populations most affected.

Thank you for your ongoing support. It has been and will continue to be instrumental to those in need.

# THE TRANSFORMATION OF BOSTONSIGHT

To address the public health issue of vision loss and impairment, we are re-imagining and optimizing our healthcare delivery protocols. The graphic below is illustrative of how BostonSight is transforming to achieve that goal.

Narrow mission, focused on limited access to expensive PROSE treatment.



Broader mission, designed to create a more scalable and affordable access to scleral lenses.

A single scleral lens manufacturing technology and location.



Global manufacturing locations and technology alternatives.

A legacy, proprietary, on-premises technology.



A cloud-based, secure technology infrastructure.

An archaic, undocumented, scleral lens design software platform.



A web-based, user-friendly fitting and order management system.

A scleral lens fitting set methodology requiring multiple trial lens production to attain a satisfactory fit.



An instrument-based fitting technology substantially reducing trial lens production, costs and chair time.

A nine-week, on-premises PROSE training requirement, substantially limiting the potential for trained practitioners.



A three-week, remote training program leveraging telemedicine technology.

Research and development constrained by limited practitioner availability.



A BostonSight Innovation Institute led by a research-driven Chief Medical Officer.

Narrowly-defined and targeted therapeutic indications for scleral lens patient applications.



Expanded, FDA-cleared, list of therapeutic indications available to a broader patient base.

A small (<30) United States base of trained BostonSight PROSE practitioners.

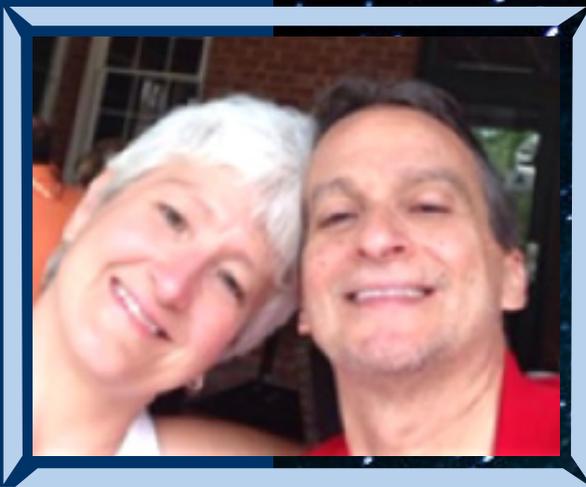


An expanding (72,000) international network of BostonSight-trained practitioners.

Fragmented financial, clinical and operations data information structures.



Integrated, data-enterprise architecture, optimizing management and operations insights and improving the quality of care.



## **JOSEPH CASTELLUCCI**

# **A REAL GAME CHANGER**

Joseph (Joe) Castellucci, a 58-year-old, now living in Nashua, New Hampshire has quite a story to share.

Joe is a cancer survivor. He was diagnosed with a rare and very aggressive form of leukemia (cancer of the body's blood-forming tissues, including the bone marrow and lymphatic system) almost a dozen years ago. Over a three-year span, Joe's treatment process included multiple rounds of chemotherapy, two full body radiation treatments and two stem cell transplants.

Joe developed a serious complication from his stem cell transplantation – chronic GVHD (graft-versus-host disease) – which can impair tissue and organ function or cause it to fail altogether. The effect of the GVHD was especially prevalent in his mouth and in his eyes, which registered as being extremely dry based on Schirmer testing (which measures tear production). He used several bottles of eye drops every week just to keep his eyes open.

Joe tried anything that anyone suggested to find some relief, including permanently cauterizing his top tear ducts. Although the procedure did help, the effects did not last, and he was right back where he started - back to using multiple bottles of eye drops on a regular basis.

Finally, in 2012, Joe's oncologist, Kellie A. Sprague, MD at Tufts Medical Center recommended that he should investigate PROSE treatment at BostonSight®. Joe still remembers with great clarity his first visit to BostonSight when his PROSE clinician, Karen Carrasquillo, OD, PhD, FAAO, FSLs applied a pair of prosthetic devices from the trial set (the starting point for creating his customized devices) in his eyes and marveled at the difference it made.

# TRANSFORMING LIVES

Joe has worn his devices for over five years now and cannot imagine living his life without them. The only time he must use eye drops now is at night when he removes his devices and then again first thing in the morning until he applies them.

Joe said, "I'm not sure what would have happened had I not come across these. When I go to see Dr. Carrasquillo each year for my comprehensive follow-up visit, she is equally amazed at the difference in my eyes. PROSE treatment is a real game changer. I can't thank Dr. Sprague enough for recommending them."

"Joe has worn his devices  
for over five years now and  
cannot imagine living his  
life without them."



**KELLY ROSE PUCILLO**

## **SURVIVING and THRIVING**

When Kelly was 22-months old, she was diagnosed with Stevens Johnson Syndrome (SJS), which progressed to the more severe form, Toxic Epidermal Necrolysis Syndrome (TENS). SJS/TENS not only attacks external mucous membranes (skin/lips), it begins by attacking internal ones. Her eyes, ears, the respiratory, urinary, and reproductive tracts were all impacted by blistering and sloughing.

By the time Kelly's parents brought their daughter to the hospital, webbing had formed over her eyes, which needed to be split several times. She was sedated, intubated and placed on a breathing machine in a pediatric burn unit for 27 days. She had 100% involvement in SJS/TENS and the doctors told her parents that if she survived, she would be blind.

Her dad maintained a vigil by her bedside, supporting and protecting his child the best way he knew how. Her mother, who was pregnant with Kelly's younger brother, was permitted short visits but the stress forced her doctors to induce labor. Her grandparents, aunts, uncles and extended family all were there with prayers and support – waiting for a miracle.

Almost a month later, Kelly's condition plateaued. She was not blind. She received a skin graft and multiple plastic surgeries especially focused on her eyes. A stubborn toddler, she refused to eat hospital or soft foods (only Cheetos) or do physical therapy despite a concern that she might not walk. Happily, on her first day home, Kelly ran into her mother's arms.

Twenty-eight years later, Kelly has lived through 45 eye surgeries, lost dozens of sunglasses, and tried a myriad of treatments and medications to help with her photophobia (light sensitivity), trichiasis (eyelashes that grow inward towards the eye), and chronic dry eye. Her eyes were always very irritated. At age six, she began wearing soft contact lenses as a bandage against the trichiasis. While they helped with daily comfort, over the years, they made her corneas worse from dryness. Without them, she could not open her left eye. With them, she was heading down the road towards a corneal transplant or possible blindness.

# TRANSFORMING LIVES

Earlier in 2018, Kelly's new cornea specialist, Kristen M. Hammersmith, MD, said, "I think we can do better," and told Kelly about BostonSight® and the PROSE prosthetic device that would protect her eye while alleviating her chronic dry eye. Kelly arrived in the Needham clinic in late July for treatment. Kelly was overjoyed to learn that not only will PROSE help to stop the progression towards a corneal transplant, but it will also help heal her corneas over time.

The devices are life-changing. Kelly said, "I no longer spend my days rubbing my eyes or feeling constant burning. No one asks me what is wrong with my eyes, because they no longer look red. My light sensitivity is already better, and I have 20/15 vision! It brings me to tears every time I think about how drastically my quality of life changed over just one week."

Kelly and fellow SJS/TENS patients recognize that surviving SJS/TENS is just the first step in a journey. Survivors face a lifetime of pain and irritation; there is bullying and self-consciousness from scars, sunglasses, tearing and eye redness. "One day you are a perfectly healthy, normal human being. Then, WHAM! Your world is turned upside down. Sunglasses, eye drops, tissues, doctors' offices, and surgeries are the new normal while you shrug it off to strangers as allergies," said Kelly. PROSE treatment has been a game changer for her eyes and for a renewed sense of independence.

Back in 1990, a journalist called her "a lucky lass." After Kelly and her husband, Brian, welcomed their beautiful daughter, Joey Rose, into the world, she thought that journalist was right. "Now that BostonSight has given me the chance to see my daughter grow up, I know that journalist was right."

"... my quality of life changed  
in over just one week."



**TOM TOPALIAN**

## **BUT NOW I SEE**

A self-proclaimed health fanatic, Tom Topalian always took pride in taking care of himself. He tried to eat right, avoided fast food, worked out almost every day, ran marathons, and never smoked. He also thought he was doing a good job of balancing the demands of a high-stress corporate communications career with a healthy family life. So, when at age 46 he was diagnosed with multiple myeloma, a blood cancer similar to leukemia, it was no surprise that he was more than surprised!

“I told the doctor that he had the wrong guy, grabbed my wife’s hand and made a run for the door,” Tom mused.

But it turned out that they did have the right guy. In 2009, Tom went through six-months of targeted chemotherapy and in 2011, as his own donor, he underwent an autologous bone-marrow transplant at Robert Wood Johnson University Hospital in New Brunswick, NJ, near his home at the time. In 2013, the cancer returned requiring another bone marrow transplant. This time his sister was a perfect match. This transplant was successful, but a year after, he developed chronic Graft versus Host Disease (cGVHD) – a common complication following a bone marrow transplant.

GVHD, while keeping the cancer in remission, attacks many of the other cells in the body. In Tom’s case, the donor’s stem cells attack the skin and mucous membrane-producing cells in the mouth and eyes, halting the production of saliva and tears.

*Editor’s note:*

*After the publishing of this piece in late December, we received the sad news of Tom’s passing. We honor him and celebrate the positive impact he had on all of his friends at BostonSight.*

# TRANSFORMING LIVES

“I never knew the importance of saliva and tears until now,” said Tom. “Without saliva you can’t taste your food, swallowing is difficult, and tooth decay is a losing battle. And without the right combination of tears and oils, simply opening your eyes is excruciating. You feel like there’s sand in your eyes all the time, making reading, driving and just watching television next to impossible.”

Tom’s oncologist tried many medications to ease his symptoms, but nothing seemed to help. Then he found an ophthalmologist specializing in GVHD and after many treatments, special eye drops and other procedures, his doctor recommended BostonSight PROSE® treatment as a last resort.

“The minute Dr. (Chirag) Patel inserted the PROSE devices, I felt immediate relief and could see better and more clearly than I had for more than two years after the transplant,” said Tom. “They not only gave me back my eyesight, but my life as well. With the PROSE devices, I’m able to drive again, read, work on the computer and do all the things most of us take for granted.”

“I know it sounds strange, but I can truly say that besides my wonderful wife and daughter, the two best things that have happened in my life is getting cancer, which has led me to closer and more loving and grateful relationships and GVHD which brought me to BostonSight. Thank you from the bottom of my heart. Thanks to you... now I can see!

“I felt immediate relief and could see better and more clearly than I had for more than two years.”



## **BENJAMIN JUAREZ**

# **I SEE WITH NEW EYES**

Recently we were delighted to meet Benjamin Juárez, a PROSE patient here in Needham, MA. He was referred to BostonSight® by his cornea doctor after a long journey with corneal disease.

Benjamin relocated from his native Mexico to become the Dean of the College of Fine Arts at Boston University where he served from 2010-2015. On September 14, 2018 at the invitation of Boston's Mayor, Martin J. Walsh, he spoke at an event at City Hall Plaza celebrating Mexico's Independence. As he raised the Mexican flag, he shared not only his love of Mexico, but the impact of Boston on his life.

Benjamin said, in part, "As a child growing up in Mexico City, Boston referred me to the struggles of the unforgettable characters of Louisa May Alcott; stories that almost moved me to tears (actually I did cry once or maybe twice). Later, my school teacher told us about Henry David Thoreau, how he opposed the war against Mexico, and preferred to go to jail rather than pay taxes to support it. A few years later, a very close family member with critical health issues found in Boston the best treatment available for her condition.

Boston became, in my imagination, the city of civility and justice. The city of knowledge and the city of healing. I could have never dreamt that one day I would be living in Boston, working for Boston University, and receiving this distinction in City Hall Plaza from the mayor himself. I feel humbled and receive it on behalf of all the Mexicans and Latinos that come here to work hard and to enrich the life of the city with their smiles, their minds and their hands.

# TRANSFORMING LIVES

In our time in Boston, my wife Marisa and I have been acquainted with many new special people who have shown us the values and generosity, the kindness and camaraderie that I read in Alcott and Thoreau. Many of them have now become part of our family because of those special moments we have shared. Our journey has been transformational in the face of joy and, while facing adversity. Knowledge and inclusion, responsible development, health, emotion, and beauty; these are Boston values I firmly believe in and encounter every day in our town.

One last word of thanks. At the age of two I lost the vision in my right eye. Numerous surgeries and procedures couldn't restore it for more than sixty years; until today. Like many patients who come from all over the world looking for hope and a last resort in our city, I found remedy here.

Today is the first day that I wear a (prosthetic) device developed here by BostonSight that fully restored my vision. Many thanks to my doctors and their team. I see Boston and I see the Mexican flag with new eyes. Long live Boston! Viva México!"

"Many thanks to my doctors and their team."

## 2017 STATEMENT OF ACTIVITIES

### INCOME AND EXPENSES

(\$ in thousands)

#### INCOME

	December 31, 2017	December 31, 2016
Needham clinic revenue, net*	\$ 2,923	\$ 2,751
Network provider clinic revenue, net*	2,096	2,532
Contributions	251	263
Other	158	96
<b>Total Income</b>	<b>\$ 5,428</b>	<b>\$ 5,642</b>
<b>EXPENSES</b>		
Program services	4,361	\$4,591
Management and general	1,247	\$1,169
Fundraising	205	\$210
<b>Total expenses</b>	<b>5,812</b>	<b>5,970</b>
<b>Net Loss</b>	<b>\$ (384)</b>	<b>\$ (328)</b>

\* Net of financial assistance totalling \$540,546 and \$594,844 in 2017 and 2016 respectively

### BALANCE SHEET

(\$ in thousands)

#### Assets

##### Current Assets:

	December 31, 2017	December 31, 2016
Cash and cash equivalents	\$ 1,321	\$ 2,169
Accounts Receivable Needham Clinic, net of reserve for doubtful accounts of \$126,500 and 248,000 in 2015 and 2014, respectively	682	656
Accounts Receivable, Network provider clinics	674	589
Accounts Receivable, other	156	21
Inventory	223	198
Prepaid expenses	68	121
<b>Total current assets</b>	<b>3,124</b>	<b>3,754</b>

##### Other Assets

Restricted Cash	185	185
Deposits	33	33
<b>Total other assets</b>	<b>218</b>	<b>218</b>

##### Property and equipment, net

	<b>535</b>	<b>434</b>
<b>Total assets</b>	<b>\$ 3,877</b>	<b>\$ 4,405</b>

#### Liabilities and Net Assets

Current Liabilities:		
Accounts Payable and accrued expenses:	\$ 473	\$ 617
<b>Total current liabilities</b>	<b>\$ 473</b>	<b>\$ 617</b>
<b>Total liabilities</b>	<b>\$ 473</b>	<b>\$ 617</b>

#### Net Assets:

Unrestricted net assets	3,199	3,581
Temporarily restricted net assets	20	22
Permanently restricted net assets	185	185
<b>Total net assets</b>	<b>3,404</b>	<b>3,788</b>
<b>Total liabilities and net assets</b>	<b>\$ 3,877</b>	<b>\$ 4,405</b>

# WITH GRATITUDE TO OUR VALUED DONORS

The following lists recognize donors whose gifts were received between January 1 through December 31, 2017.

## LIFETIME GIVING

### **\$1,000,000 and above**

Bausch + Lomb

### **\$250,000 - \$999,999**

Lorne Abony

Frank and Diana Berry

Bruce and Holly Johnstone

Michael and Myra McCoy

Nehemias Gorin Foundation and  
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### **\$100,000 - \$249,999**

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Irena Bronstein and Eugene Bonte  
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TRANSFORMING LIVES

# VISIONARY CIRCLE OF HOPE

Visionary Circle of Hope donors make gifts of \$1,000 or more in a calendar year. Leadership donors help BostonSight's commitment to restore sight and help transform lives.

## **\$25,000 and above**

Indo-American Eye Care Society  
Michael and Myra McCoy

## **\$10,000 - \$24,999**

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The Barbara Epstein Foundation Inc.  
Henry and Diane Bisgaier  
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# TRANSFORMING LIVES

## BOSTONSIGHT DONORS

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Doreen Cutler  
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John Delude  
Marcia Denberg  
Jennifer Dickson  
Jeriann Dodd

Your gift to BostonSight  
is the critical link to  
transformational care and  
the hope of a better future.  
Thank you!

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*Every effort has been made to ensure the accuracy of our donor listings. If there is a misspelling, omission or improper listing, please accept our sincere apologies and call 781-726-7512 so that we may correct our records.*

# TRANSFORMING LIVES

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Eli, Bonnie and Rebecca Okrant  
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