



Boston Foundation for Sight Survey Report Back to the Community

7/15/2010

Boston Foundation for Sight www.bostonsight.org

Beth Beard

“Vision is so important to life. We rely on it virtually all the time. We need it not just for basic functional tasks, like working or driving, but for socializing, relaxing, and enjoying life. Reducing vision reduces so much and can really suck the life out of you. So many enjoyable things turn into a struggle and become stressful rather than relaxing and re-energizing. Bad vision is 24/7 and it wears on you, beats you down, and you can't escape it. Maybe you can get used to it. But you can't get over it. You can't forget it. It's always there to remind you, make things difficult for you, and make beautiful things ugly, confusing, and stressful.”

~ BFS Patient



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INTRODUCTION

The [Boston Foundation for Sight](#) (BFS) aims to create the most satisfied patients in the world. To help reach that goal, BFS launched an online survey in November 2009 and conducted additional research to ensure it has the deepest understanding of the needs and experiences of those struggling with corneal disease and other vision challenges. Ultimately, BFS intends to use the survey feedback to facilitate support systems and peer networks beneficial for not only BFS patients and their families, but also for the broader community of people struggling with eye-related challenges. BFS contracted consultant Beth Beard to design and analyze the survey and then hired her as its Director of Communications and Community Networks to ensure that BFS is responsive to the needs of its community.

ABOUT THE BOSTON FOUNDATION FOR SIGHT

The Boston Foundation for Sight (BFS) is an internationally renowned not-for-profit eye healthcare organization dedicated to restoring vision and improving quality of life for our patients and their families. We strive to transform the understanding, treatment and care of complex corneal disease within the global medical community and the public at large. Since our founding in 1994, we have been innovative leaders in research and treatment of corneal conditions.

Our 12,000 square foot facility in Needham, MA, includes a state-of-the-art manufacturing lab, a medical institute staffed with seven doctors and a dozen technicians/trainers, a Clinical Research Center and a new Patient and Community Support Center. We enjoy educational partnerships with the renowned Massachusetts Eye and Ear Infirmary and the New England College of Optometry; each year Cornea Fellows and Optometry Residents come to BFS to be educated in the latest in treatment of corneal disease, and they join our medical staff in cutting-edge clinical research on the next generation of tools in the fight against these insidious diseases of the ocular surface system.

Our Treatment Model

Prosthetic replacement of the ocular surface ecosystem (PROSE) is a pioneering treatment model developed by the Boston Foundation for Sight to restore vision, support healing, reduce symptoms and improve quality of life for patients suffering with complex corneal disease. PROSE vision rehabilitation uses FDA-approved custom designed and fabricated prosthetic devices to replace or augment the impaired ocular surface ecosystem function. For many of the thousands of patients with conditions such as Stevens-Johnson syndrome, chronic ocular graft-versus-host disease (GVHD), Sjogren's syndrome, keratoconus, pellucid marginal degeneration, ocular trauma, complications of LASIK, or complications of cornea transplantation, PROSE can be the ideal, and sometimes only, treatment capable of restoring vision and dramatically reducing pain and light sensitivity.

PROSE interdisciplinary treatment teams include a cornea specialist ophthalmologist, an optometrist who has completed an intensive 9-week PROSE Clinical Fellowship at BFS, medical assistants, trainers,

and prosthetic device manufacturing engineers and technicians. PROSE treatment teams work with each patient, his/her support system and other medical providers to form a collaborative care network where all members work to understand each patient's specific needs and reach treatment goals together.

PROSE Clinic Network

As of July 2010, we have established eight groundbreaking partnerships with top-ranked specialty eye care centers located in academic medical centers in the US and clinics abroad to offer PROSE. Two clinics are located in Texas: one at the Baylor College of Medicine's Alkek Eye Center in Houston; the other, at Brooke Army Medical Center in San Antonio, serves active duty military personnel, including Wounded Warriors. There is a PROSE clinic at the University of Southern California's Doheny Eye Institute in Los Angeles. Three international clinics are located in India in Hyderabad and Mumbai; and in Nagoya, Japan.

Our newest partners, the University of Michigan's Kellogg Eye Center in Ann Arbor, MI and Weill Cornell Medical College's Weill Cornell Eye Associates in New York, NY will begin seeing patients in September and October of 2010 respectively. Each PROSE clinic is *independently operated* by our partners who manage scheduling and insurance and provide ongoing care.

Get Connected

Click here to sign up for our new [BFS E-Bulletin](#).

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ABOUT THE AUTHOR

Beth Beard is a nonprofit consultant with 15 years of experience in organizational development, education, nonprofit management, project management and network capacity building. She holds a B.A. in Philosophy and an M.Ed. in Counseling Psychology, Marriage and Family Systems Therapy from the University of Massachusetts Boston and worked early in her career as an after-school manager and clinician for high-risk adolescents and families. Later her work focused on organizational development and capacity building as a project manager for youth development organizations and an independent consultant for a range of Boston-based and national clients in the public, private and nonprofit sectors.

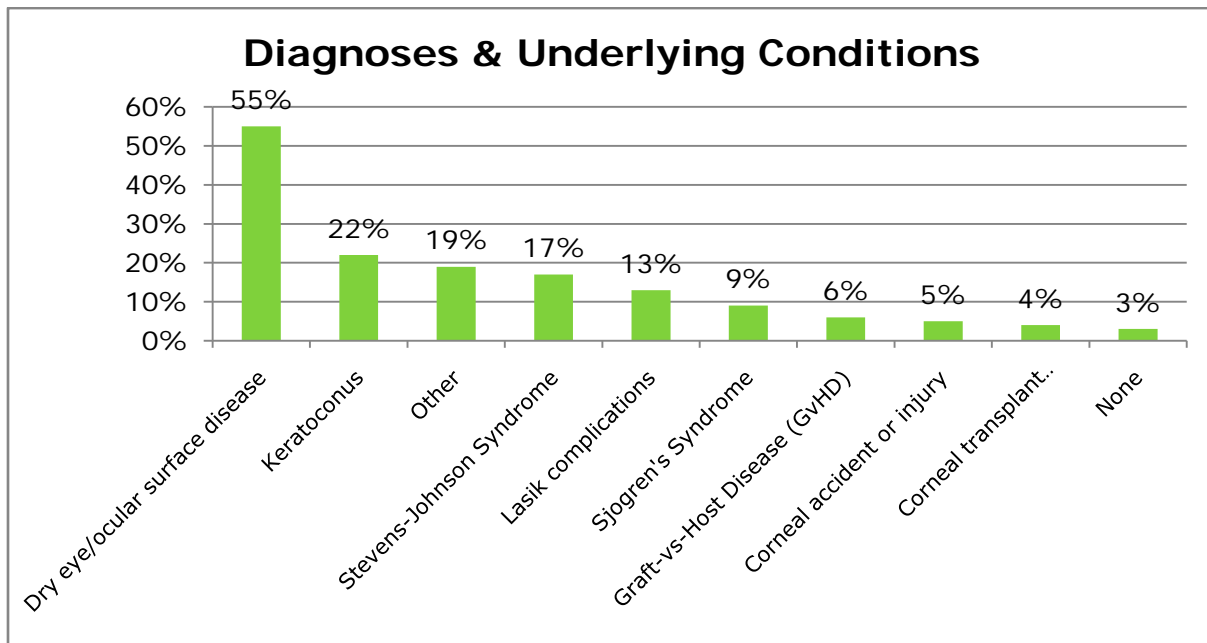
NOTE ABOUT DATA COLLECTION AND LIMITATIONS

BFS recognizes that there are many members of your community whose ability to use the internet is limited or prevented entirely, due to eye-related challenges or limited access to necessary assistance and accommodations. In order to capture the knowledge and experiences of those who may not be represented in the survey data due to these barriers, Ms. Beard conducted interviews with ten BFS doctors and senior staff members to tap their collective knowledge gained through 10+ years of experience working with thousands of patients and families struggling with severe eye-related difficulties. She also conducted web research and interviews with leaders in the dry eye community and took steps to minimize online accessibility barriers by using [Survey Monkey](#), the only online survey application tool [certified as accessible](#) by the federal government for users with visual limitations or other disabilities.

This survey did not utilize random sampling methodology. Instead, survey respondents were self-selected from four specific groups: BFS patients and family members with active emails on file, Dry Eye Zone members, Stevens-Johnson Syndrome Foundation members and Keratoconus Foundation members. This method inevitably resulted in an over-sampling of certain groups and may make the survey results less generalizable; this is particularly true for questions relating to website traffic, specific diagnoses/diseases and treatment courses. Please keep these limitations in mind as you review this report. BFS plans to include phone surveys, in-person interviews and focus groups in future outreach efforts to ensure that BFS is reaching the widest cross section of their community as possible.

SECTION I: YOUR COMMUNITY

Your community mainly consists of people with a variety of rare diseases and underlying conditions, often with long, uncertain, and difficult treatment courses. Through the survey, you show us that you are united by the shared symptoms of corneal disease-vision impairment, dry eye, pain and light-sensitivity-rather than by a single underlying diagnosis. You represent the full demographic spectrum across race, ethnicity, age, socioeconomic status, gender, and geographic location. In addition, the vast majority of you report experiencing multiple barriers to obtaining appropriate treatments, follow-up care and support.



You report feeling marginalized by the medical community and are particularly vulnerable to health care coverage issues for eye-related treatment and care. In spite of this, you have collectively tried dozens of treatments, though few of them with significant success. We were moved, but not surprised to read that you often feel isolated, discouraged, frustrated and, at times, even hopeless. Like many chronic medical conditions, your family members and loved ones experience significant impacts as well.

However, the challenges you and your families have faced have led you to develop a number of coping strategies and skills that are uniquely adapted to your individual and collective experiences. Many of you have become your own best advocates, medically savvy with significant experience researching eye related diseases and treatments and navigating complex health care systems.

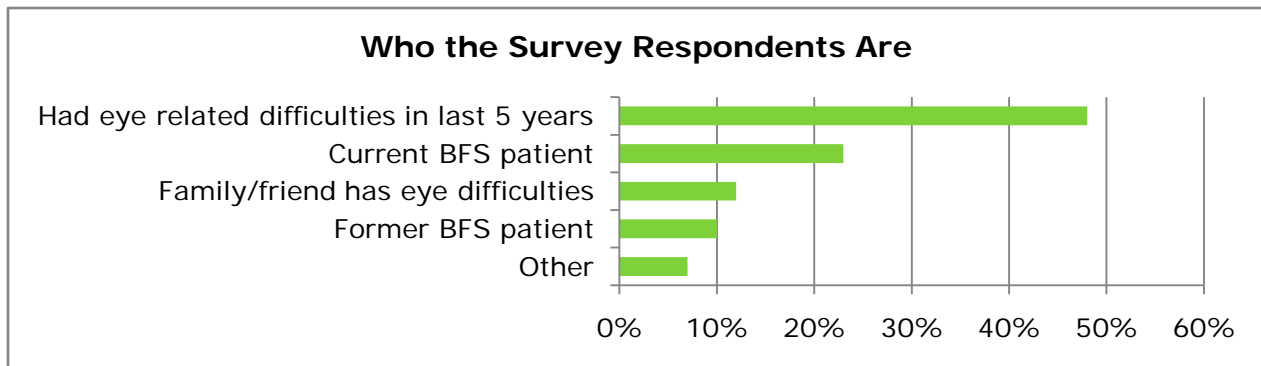
You also frequently report feeling very personally connected and dedicated to the doctors, clinics, organizations and treatment options that have given you some relief- and with it the hope that you can have a better quality of life. Thousands of you have gravitated to online support networks- in effect creating the systems you need to help yourselves and support one another in ways the medical community has not or cannot. In short, you are extremely adept at articulating what has worked, what has not, and what support you still need to overcome these challenges and live healthy, fulfilling and productive lives.

So who makes up your community?

SURVEY RESPONDENTS

When BFS asked for help, the community response was overwhelming- 1,127 of you started the survey and over 1,000 of you completed it in a matter of hours and days. Most of you learned about the survey from one of the following sources:

1. The [Boston Foundation for Sight](#) website and email outreach
2. The [Dry Eye Zone](#) newsletter, website and listserv
3. The [Stevens-Johnson Syndrome Foundation](#) website and listserv
4. The [Keratoconus Foundation](#) listserv and website



TREATMENT COURSES AND PREVALENCE

There is no known cure for corneal disease, but there is a long list of things to try for treating and managing the primary symptoms- vision impairment, pain, dry eye, and light sensitivity. Collectively, you have undergone a wide variety of treatments and procedures, often stretching over many years. The 811 of you responding to the question on treatment course reported on 34 different treatments or procedures in the last 5 years and you have collectively undergone 4,568 treatments during that time- an average of six treatments for each of you. These vary in severity and invasiveness from very

mild/minimal (artificial tears or flaxseed oil), to moderate (BFS treatment or punctal plugs), to severe (tarsorrhaphy [sewing the eyelids shut], corneal transplants).

While some treatment options are much more prevalent than others (i.e., 90% of you have tried artificial tears vs. 1% who have had a limbal stem cell transplant) the overall success rates for almost all are disappointing at best. For example, less than 1 in 8 of you report significant success with the three most common treatment options (artificial tears, oral antibiotics and topical steroids). The BFS treatment (Boston Ocular Surface Prosthesis) is the only option that had a majority of respondents- 80%- reporting significant success. Below is a list of all of the treatments and their success rates that you shared with us.

Treatment	Prevalence	Significant Success	Moderate Success	Little/No Success
Artificial tears or lubricants	790	10%	25%	65%
Lenses (soft contacts, rigid gas-permeable contacts, sclerals)	638	15%	22%	63%
Oral antibiotics, flaxseed oil, tetracycline, doxycycline, or fish oil	474	5%	30%	65%
Topical steroids	451	11%	38%	51%
Punctal plugs	443	6%	28%	66%
Topical immunosuppression (Cyclosporine/Restasis)	440	6%	25%	69%
Topical antibiotics	371	8%	38%	54%
BFS Treatment (Boston Ocular Surface Prosthesis)	306	80%	15%	5%
Punctal cautery	138	11%	27%	62%
Bandage soft contact lenses	123	19%	28%	53%
Lacriserts	109	6%	13%	81%
Lasik	95	16%	22%	62%
Autologous serum	73	11%	36%	53%
Lash electrolysis /cryo	44	20%	41%	39%
Tarsorrhaphy (sewing lids shut)	36	14%	22%	64%
Surgical or laser revision of corneal transplant	32	37%	26%	37%
Mucous membrane grafting / marginal lid rotation / fornix reconstruction	31	32%	36%	32%
Amniotic membrane graft	30	20%	43%	37%
PRK (photorefractive keratotomy)	24	21%	17%	63%
RK (radial keratotomy)	23	39%	35%	26%
Limbal stem cell transplant	9	33%	33%	33%

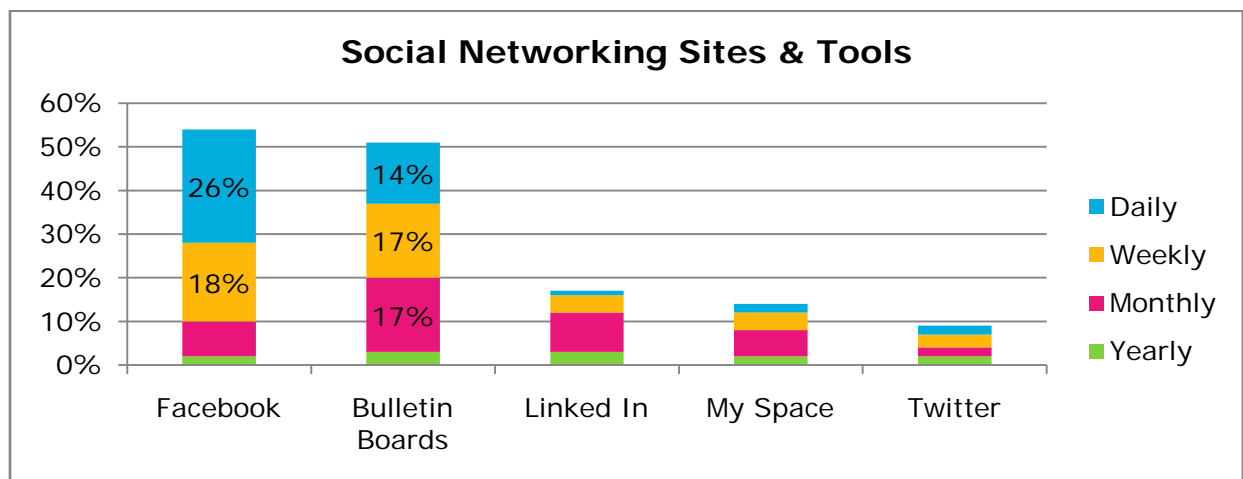
ONLINE RESEARCH AND NETWORKING HABITS

All of the members of your community who responded to the BFS online survey use the internet in some way to communicate, connect, and find information. However many of you with severe eye-related challenges are limited in your ability to take full advantage of this social medium or use it at all without some sort of accommodations.

SOCIAL NETWORKING SITES AND TOOLS

Barriers to internet use are particularly prevalent on the major social media sites, all of which have [significant accessibility limitations](#) according to widely accepted [Web Accessibility Initiative \(WAI\) guidelines](#) created by the World Wide Web Consortium (W3C) and US federal guidelines [Section 508](#). Many bulletin board application and research sites have similar limitations. The more these barriers are minimized or eliminated entirely and the greater the access to adaptive technology and tools the community has, the better you will be able to take advantage of these resources to self-organize, advocate and support yourselves and one another. For more information, please see the Note About Data Collection and Limitations in the Introduction.

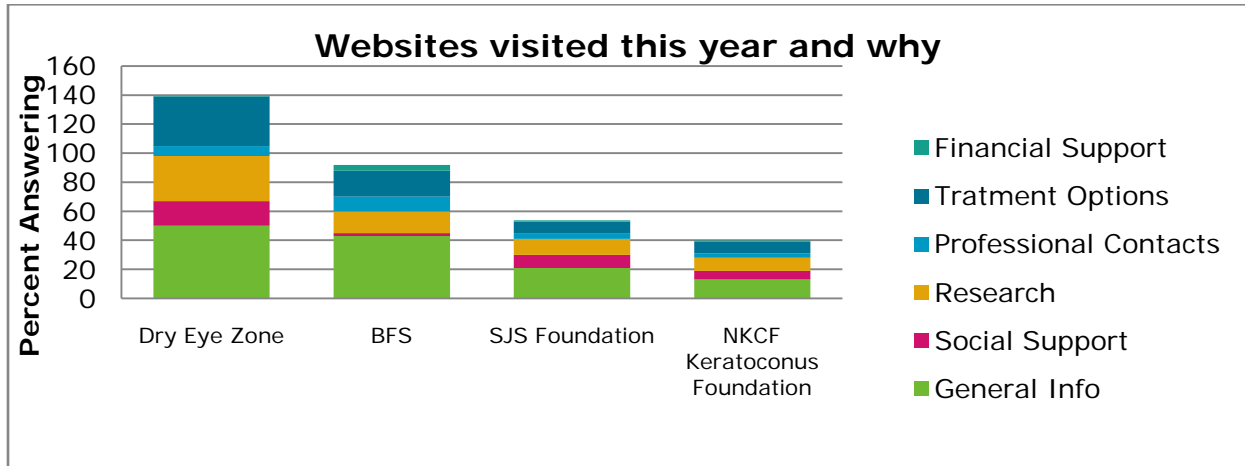
Below is a list of online social networking sites and tools in order of popularity and frequency of use.



Other social media sites identified in the survey include: Plaxo, Jaiku, Orkut, CouchSurfing, Classmates, Hi5, Yahoo Groups, Google Groups, Craigslist, Friendster, and YouTube.

EYE/VISION-CENTERED WEBSITES

The survey also asked about whether you have visited a number of eye-specific websites in the last year and if so, how you have used them. Options included: general information, social support, research, professional contacts, treatment options and financial support. Overall, you visited the Dry Eye Zone more frequently than any other site and once there you used it in the most ways. As a group you were least likely to have visited the Bone Marrow Transplant Info Net and Lighthouse for the Visually Impaired and for those that did, you used the sites in the smallest number of ways.



ONLINE SEARCHES FOR EYE-RELATED INFORMATION

Almost all of you (93%) have conducted online searches (Google, Yahoo, etc.) during the last 2 years to find out more information about eye conditions, diseases, resources or treatments. Below you will see information about the most often used search terms.

Most Common Search Terms	# Who used it
Dry eye, severe or chronic	584
Scleral lens	312
Eye pain	288
Corneal disease, damage, thinning, scarring, or ulcers	244
Photo or light sensitivity	225
Keratoconus, KC, corneal ectasia, keratoglobus, or pellucid marginal degeneration	169
Stevens-Johnson syndrome or TEN	152
Corneal transplant	142
Sjogren's syndrome	140
Contact lens	130
Vision loss or impairment, impaired vision, low or limited vision, blindness	126

LASIK complications	113
Ocular surface disease	81
Restoring sight or sight restoration	57
Graft-versus-Host-Disease , GVHD or bone marrow transplant	51
Anesthetic corneas	35
Familial Dysautonomia	8

Notice that the most frequently searched terms are symptoms-dry eye, eye pain, and light sensitivity. Specific eye diseases and conditions are highly searched for, but are second in frequency to eye symptoms.

Search Terms	% Ranking it 1st or 2nd
Dry eye, severe or chronic	86%
Keratoconus	81%
Stevens-Johnson Syndrome or TENS	76%
Lasik complications	68%
Graft-versus-host-disease	55%

SECTION II: BARRIERS TO TREATMENT AND CARE

FINANCES AND TRANSPORTATION

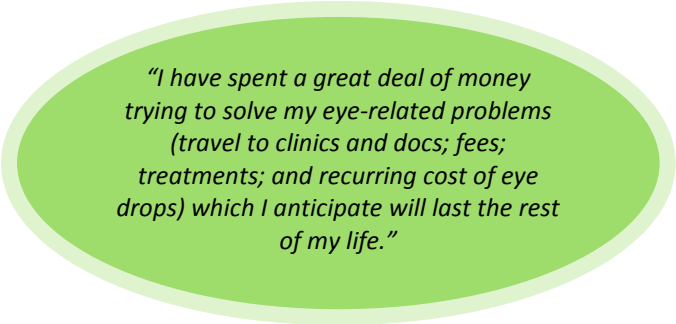
Having severe eye related difficulties can be expensive- and for some you it presents a considerable financial burden. There are many direct, indirect and hidden costs that can affect patients and families, and most are not sufficiently covered by health insurance. Some of these include:

- Lost work time due to appointments, treatments and fittings
- Over-the-counter and prescription medications
- Specialized medical procedures, consultations, surgeries or treatments
- Light dimming shades
- Special goggles, glasses or lenses
- Individual, group or family therapy
- Personal or home care assistance
- Specialized computer software or books on tape
- Job search assistance/coaching
- Adaptive workplace needs

Alternate and local medical transportation costs are also often higher due to vision limitations: 39% of you reported moderate or severe difficulty driving during the daytime in familiar places and 71% of you

experience moderate or severe difficulty driving at night, requiring you to find- and often pay for- alternate transportation.

Dozens of you also indicated that life-altering treatment was delayed or inaccessible due to financial and/or travel related barriers. Some of you reported losing your jobs due to vision difficulties- and with it your health insurance coverage. Some of you received the treatment you needed but at great financial and personal cost, including bankruptcy and mortgage foreclosure.



"I have spent a great deal of money trying to solve my eye-related problems (travel to clinics and docs; fees; treatments; and recurring cost of eye drops) which I anticipate will last the rest of my life."

Other survey question responses further illuminate both the long-term financial toll and your unmet needs:

- 39% of you indicated that it was “definitely” or “somewhat” true that your household income has decreased due to eye related challenges.
- 58% of you are very interested in financial or insurance help for eye difficulties and another 21% are somewhat interested.

For current and potential BFS patients and families, the vast majority of you who could benefit from the services and supports offered by BFS live outside of Massachusetts and face a number of additional costs that can be barriers to receiving treatment and follow up care. These include flights, local transportation, lodging and meals during the 5-10 day clinic visits for patients and often additional family members. The annual costs for BFS patients to receive care includes the price of the lenses, the fitting, follow up visits, and varied transportation, travel, lodging and meal expenses depending on their proximity to a BFS clinic location, plus the annual cost of solutions for ongoing lens care.

Although approximately two out of three of the patients coming to BFS’s Needham, Massachusetts clinic are now covered by insurance, that was not always the case. In addition, a number of insurers elsewhere in the U.S. do not yet routinely cover the full cost of the BFS treatment. For some patients and families this amounts to \$8,000 or more in out-of-pocket expenses and +/- \$2,000 every 5 years. This is usually on top of the hundreds or thousands of dollars they have spent on unsuccessful treatments before coming to BFS.

HEALTH BELIEF SYSTEMS AND HEALTH CARE SYSTEM NAVIGATION

Far too many of you have spent years navigating the health care system and have found it to be at times discouraging, frustrating, and confusing, and often staffed by providers who are insufficiently knowledgeable and/or unwilling to take you and your problems seriously. You shared your feelings of discouragement and distrustfulness that the medical field can really help you.

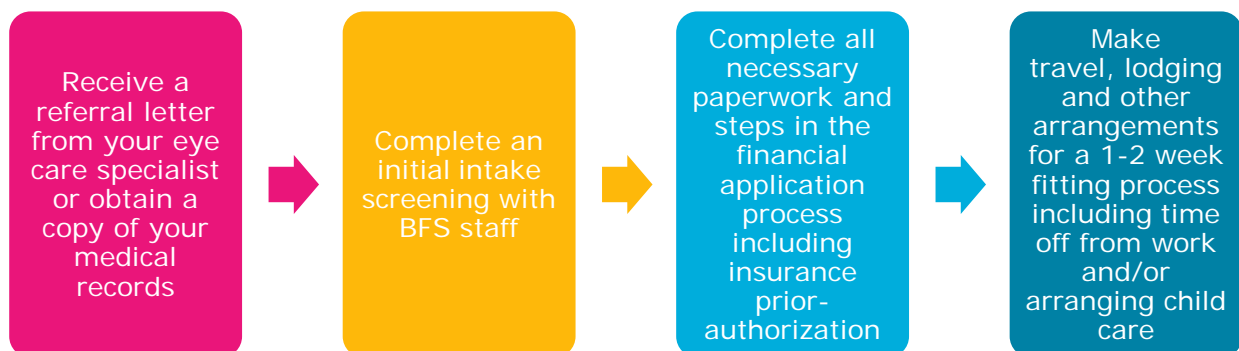
Many of you (and the majority of BFS patients) also suffer from rare, little known diseases or conditions that make treatment more complicated. As one of you describes, *“I have tried to talk to a psychologist about my eye problems but she just thought I was obsessing and wanted to put me on anti depressants, which is the same response I got from my doctor. When I tell my doctor that anti depressants can cause further dry eye, she says, ‘Oh, I never heard of that.’”*

Rare diseases or conditions also frequently receive less attention within the medical community and consequently have less funding available for research or treatment innovations. Insurance coverage for treatment of symptoms associated with rare diseases is also more likely to be denied due to a combination of factors that can include limited use/demand and treatments designated as “investigational” or patient specific “exceptions,”.

Finally, rare diseases are just that- rare- making it difficult for the people and families struggling with them to find the information, resources and supports they need. This is particularly true of social and peer support. You may find you are the only person you know- possibly the only person within a hundred miles- struggling with your illness and its unique collection of symptoms, increasing your sense of isolation and limiting access to crucial knowledge resources, treatment options and referral networks.

“I know of no one else that has been diagnosed with SJS. I find information from websites to help me. The cost of going to Boston is too much for me and my family. Please help us with our quality of life.”

There are also multiple steps for current and potential BFS patients to navigate in order to present themselves in Boston to receive care including:



These steps can take 2-3 months time and patients may run into challenges at any time in the process due to a number of factors including:

- Finding and/or persuading an eye care specialist to provide the necessary referral
- Complications, delays or hurdles with obtaining medical records, financial records or insurance prior-authorization
- Barriers or challenges to finalizing travel arrangements including: health related issues, costs, transportation limitations, and/or lack of sufficient childcare or time off from work

PHYSICAL HEALTH, SOCIAL AND QUALITY OF LIFE ISSUES

Unfortunately, the majority of you have multiple associated issues that can make reaching out to you and getting you connected to appropriate care particularly difficult. When asked about how you have been affected by eye related difficulties you responded “definitely true” or “somewhat true” to the following:

- 72% accomplish less than you would like
- 69% are very focused on you or your family member’s eye related difficulties
- 61% have less control over what you do
- 58% travel or go places less often
- 58% enjoy life less
- 55% are less physically active

Many of you also face physical and emotional symptoms that affect multiple areas of your lives:

- 79% experience moderate or severe pain and discomfort in or around the eyes
- 71% have moderate or severe photosensitivity
- 68% have moderate or severe difficulty reading print newspapers, magazines or websites
- 65% have moderate or severe difficulty with work or hobbies that require seeing well close up such as cooking, fixing things around the house or using hand tools

Over 550 of you added additional comments about other areas of your lives that have been affected by eye related difficulties. The shame, depression, isolation, and hopelessness described by hundreds of you often undermine your capacity to ask for help or seek out new treatments and providers. The most common- and debilitating- effects you describe include:

- Depression, suicidal ideation, chronic fatigue, sleep deprivation, anxiety and other mental illnesses
- Guilt, anger, frustration, irritability, fear, shame, and worry about the future
- Lack of understanding or support from others
- Chronic and/or severe physical pain
- Fear of losing independence, personal freedom and the freedom of family members
- Difficulty obtaining and/or maintaining employment and decreased confidence about job skills
- Forced retirement or loss of professional career
- Interpersonal issues with colleagues or friends
- Inability to spend long periods of time outside of your homes
- Looking/feeling unattractive and lowered self-esteem
- Difficulty with basic daily living tasks and household responsibilities such as shopping, cooking, cleaning and child care
- Emotional and physical toll on family members
- Home instability including forced sales, foreclosures and needing to move due to a lack of appropriate accommodations, discrimination and other issues
- Loss of health insurance
- Poor health or complications due to multiple interrelated conditions, diseases or symptom

“It has been disabling. I'm a doctor and haven't been able to read for over two years. Eventually I stopped working because I couldn't tolerate the addition stress due to the depression and irritability caused by my eye problems.”

“It is depressing to be young with red, tired bleary dried out looking eyes. Everyone used to tell me that I had pretty blue eyes, but not anymore.”

“My family suffers anytime they see me struggle. They are not used to seeing me despondent or weak.”

You may relate to what others shared about some quality of life issues:

75% of you are more stressed out

- “I am struggling with the slow growing realization that I don’t see as well as others and the fear of losing my independence down the line.”
- “I feel that there is no prospect of me ever leading anything like a normal life.”
- “I am worried because I am so young and I am already having eye issues. I try not to let my husband know how worried I am.”
- “I am in emotional and physical torment.”

39% had your household income decrease due to eye related challenges

- “I have lived with constant pain from dry eyes the last 3 years. I go from doctor to doctor looking for relief. I am unable to do certain jobs at work. I stay at home because of the pain.”
- “I retired early because of my poor vision...My husband is laid off and my current vision precludes me from getting a job even though I am a master’s prepared nurse.”
- “I am just not able to work to my full potential.”

80% of you describe worrying about eyesight as moderate or severe

- “I don’t like the person I am becoming: short-tempered, upset over what seems like little things (e.g. having a fit when I can’t seem to find whatever I am looking for), raising my voice to whoever is at hand if my shopping list or recipe has not been followed exactly.”
- “I know my whole family has been affected by my loss of vision. As the mom of the family I believe that my role has been to nurture and help guide the family and to be strong in all areas. But with the loss of independence my family members now have to compensate for my loss. The sense of guilt is at times so frustrating “
- “My children and wife have difficulty understanding the problem, even though they try very hard...I try to fight through the problems and keep life as normal as possible, which I feel my family interprets as meaning the problem is less significant than it is.”

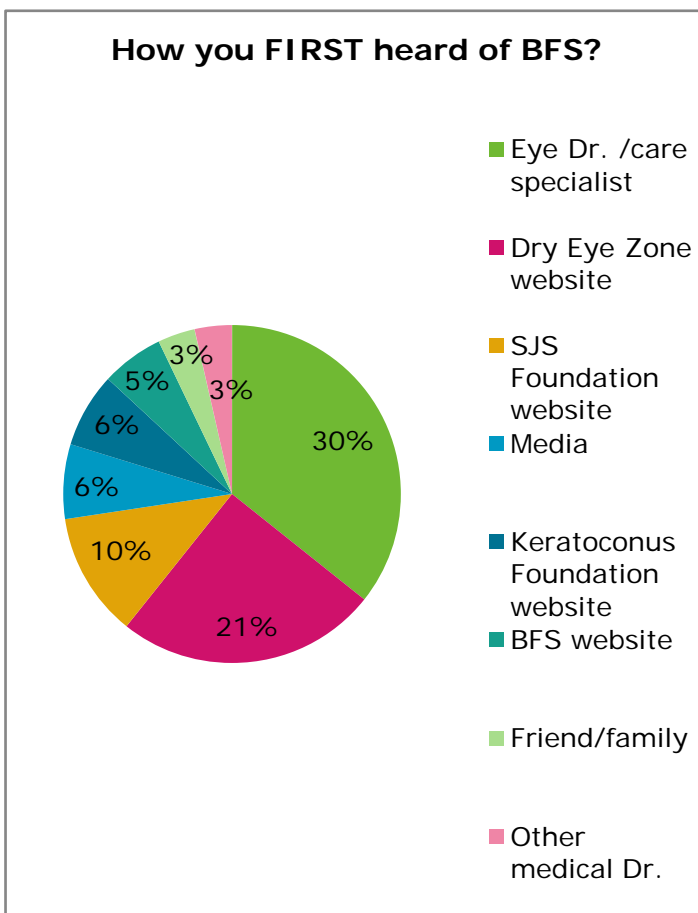
Eye related challenges also have significant negative impact on the social networks and supports that are critical for meeting both your immediate medical, physical and psychological needs and for lifelong health and wellness:

- 63% of you go out less often
- 56% have moderate or severe difficulty going out to see movies, plays or sporting events
- 52% have less opportunity for social interaction
- 43% have moderate or severe difficulty visiting with people in their homes, at parties or in restaurants
- 30% argue with your spouse, partner or children more than you used to
- 29% have moderate or severe difficulty seeing how people react to things that are being said

BARRIERS TO RECEIVING BFS CARE: AWARENESS, OUTREACH AND EDUCATION

Some of the most significant barriers to receiving care, particularly from the BFS, are also the most basic- awareness, outreach and education. When asked about your familiarity with the BFS, 311 of you (34%) said that you are “not at all familiar” with BFS. For the remaining 618, you first learned about BFS from the following sources:

Strikingly, among those of you who are not BFS patients, more than half of you (57%) are “not at all familiar” with BFS. Only 1/3 of you have visited the BFS website in the last year, while 68% have visited the Dry Eye Zone, 30% visited the Stevens-Johnson Syndrome Foundation website and 15% visited the Keratoconus Foundation website. Among those who are familiar with the organization, only 6% first learned of BFS from another patient or family member and only 5% from the BFS website.



LIMITED VISIBILITY AND ACCESS COUPLED WITH COMPETITION

The limited visibility of BFS generally, and BFS's treatment approach specifically, extends to the eye specialist community as well. For the thousands of individuals that do not live close to a tertiary eye care specialty center or clinic they have less access to and/or awareness of the specialists that are most qualified to treat their conditions- the same specialists that would also be most likely to know about BFS and refer them for care.

This issue can be compounded by competition among specialist providers resulting in a reluctance to refer patients to alternate providers and potentially thousands of patients who are led to believe- whether intentionally or unintentionally- that they have exhausted all of their options and ultimately stop looking for additional treatment.

One extraordinarily persevering BFS patient illustrates how formidable this barrier can be: *"I had been to 54 doctors before being referred to BFS."* This comment also illuminates how intertwined and mutually reinforcing these barriers can- imagine the associated financial, travel, physical, social, occupational, and emotional costs that must have come with those 54 doctors- for both the patient and his/her family.

SUMMARY CONCLUSIONS

Collectively the barriers outlined above have the potential to impede or obstruct every step in your journey:

- Researching and finding the help you need (limited travel, limited vision, inability to follow the latest research or conduct research online, negative experiences in the health care system, etc.);
- Having the motivation, energy and physical capacity to pursue further treatments or the belief that you will improve (multiple compounding medical conditions, depression, hopelessness, anxiety, fatigue, etc.);
- Getting the social, emotional and professional supports needed to continue to manage and treat your condition(s); and
- Having the financial and physical resources needed to adequately pursue and pay for treatments over time.

"I would like to see BFS gain more prominence in the treatment of corneal disease. Specialists that we consulted in our state had never heard of the special lens, and were very dismissive of our requests to try it."

"Tarsorrhaphy (sewing the eyelids shut) was the next step for me with my eye doctor. Lucky for me we found the BFS"

SECTION III: COMMUNITY PERCEPTIONS OF BFS

BFS THROUGH THE EYES OF THE PATIENTS

When asked what first comes to mind when thinking about BFS, patients and family members have a lot to say- and the responses were overwhelmingly positive. As an organization, BFS is often described as a unique pioneer in the field of corneal research, treatment and care. It is seen as the place of last resort for many of you who, after years of struggling with chronic, often debilitating medical issues, finally find relief- regardless of your ability to pay. Overall, patients and family members have an extremely high level of connection to BFS- 20% of you report, “knowing the mission by heart.” Most importantly, you collectively paint a picture of BFS as much more than a medical clinic or organization in the traditional sense. As one of you sums up well: *“Sight restored. Lives regained. A wonderful caring place where you feel like family. Where miracles happen every day.”*

You told us that when you became a patient of BFS you became the newest member of an extended family full of deeply caring, committed, sincere and compassionate professionals who work tirelessly to get to know you as a unique human being and really understand your eye difficulties in the larger context of your life. You dare to hope.

You have the opportunity- sometimes for the first time in your life- to connect with other patients and family members who truly understand what you are going through. You no longer feel alone. You quickly come to believe that the BFS family will do everything they can to help you get your sight and your life back; and because of that, no matter how much or how little BFS is actually able to do for you medically, you are grateful to have found them.

“A state of the art facility that opens the heart, soul and eyes of all who walk through its doors.”

“The BFS is the warmest, most comforting place to be if you have severe dry eye/pain. They get it, and they give you hope that treatment is available.”

“The BFS provided me with a new lease on life. I wouldn't be able to live without their care.”

HOW OTHERS SEE BFS

While a small number of you who are not patients described BFS using language and sentiments very similar to BFS patients, the majority of your responses are in striking contrast to the way patients see

BFS. The language you most often used to describe BFS and the major themes include: specializes in severe eye conditions and corneal disease/damage; expensive, time consuming, and last-resort option; leader in research, manufacturing and fitting scleral lenses; located exclusively in Needham/Boston; provides some financial help and; specializes in specific diseases and conditions (Keratoconus, Sjogren's syndrome, SJS/TEN, severe dry eye, GVHD) and only treats severe cases.

Over 30 of you described BFS exclusively as an organization that provides lenses:

- *"Developer of special lenses for special eye problems."*
- *"Scleral lens. Expensive. Last resort."*

SECTION IV: COMMUNITY FEEDBACK

WHAT BFS DOES REALLY WELL

When those of you who are familiar with BFS are asked to describe what BFS does really well and why, you reiterate many of the sentiments expressed above. You believe that BFS excels in:

The overall medical experience

- *"It's difficult to narrow down what they do well because they do everything so well. Advanced medical care and hospitality are stellar. The highest quality I've seen in my experiences."*
- *"The coordination and orientation and logistics for new patients. Fitting process of the lenses, training how to use the contact lenses, and they really do well making you feel "at home" while you are at the clinic at all times."*
- *"The whole process of fitting and making the lens and pacing the patient through the steps is done extremely well. Why? The doctors and technicians are incredibly talented at what they do. But it's more than that. It's a little more than you expect. It's nice."*

High quality, professional, caring, gentle and compassionate medical services and personalized emotional patient/family support

- *"The efficiency of your process, you changed my life in a week. Your staff are all friendly and encouraging. My wife and I felt very comfortable while in the presence of the best specialists in the world."*
- *"Their gentle guidance and support is just amazing. I have been lucky enough to have been seen by some amazing doctors, but not one of them can ever come close to the respect and gentlest treatment they have shown me at the BFS."*

- *“They know exactly what you are going through. They can see your pain and frustration and they put all their medical skills to find a solution. They feel like angels.”*

Producing incomparable success rates with restoring vision and quality of life using unique, highly specialized technology and cutting-edge research for continuous quality improvement

- *“BFS is doing a phenomenal job of developing the technology and disseminating it to leading centers while also treating patients at BFS.”*
- *“Analyze, design, and manufacture solutions in only hours.”*
- *“Profound knowledge of severe eye conditions, that some other doctors or institutions have not the chance to solve. I am working on the eye care industry and have experienced and know different treatments/ doctors, but with no results on certain conditions that BFS does.”*

Creating unique opportunities for peer support, networking and education

- *“Besides the miracle lenses that they produce and fit, they make the whole experience much more comforting and less stressful than I thought it would be. The conference room, T.V. room, quite computer room and all the beverages and snacks make it a nice environment to spend the day...The conference room enables and almost encourages people to sit and chat, which is much different from a regular waiting room.”*
- *“Treatment is the backbone, but the environment was like a support group. I actually didn't want to leave. Everyone was kind, understanding and sensitive to the issues that patients have when dealing with a long term eye problem. The whole place was approachable. I was initially worried that it would be a big corporate feeling "foundation." I hope the place always stays as down to earth as it is.”*

Providing financial, insurance and other supplemental supports to promote equitable care regardless of income or geographic location

- *“Help people even though they may not be able to afford the cost.”*
- *“The fact that the BFS treats people who have the inability to pay, because they believe everyone has the right to see.”*

WHAT BFS COULD IMPROVE

When those of you familiar with BFS were asked if there was anything the Boston Foundation for Sight could do to improve or change, the answer from more 100 of you was- nothing:

- *“No, it can't get any better.”*
- *“It is perfect the way it is. I just wish more people knew how great they were.”*

- *“Just to know that you are there for all of us is most assuring!”*
- *“Actually, no. Well, perhaps better food in the kitchen by the end of the week! :-).”*

For those that did express room for improvement, your responses overwhelmingly fell into one of two categories of changes you would like to see: 1. more communication and patient/family support services and; 2. the capacity to serve more patients through additional clinic sites, increased visibility, education and outreach.

Additional Support Services Suggested

- *“I believe it would help to offer more contacts with other people that have experience with the lens. Support groups are very important.”*
- *“Additional information such as support groups, newsletter, one on one consultations would be greatly appreciated.”*
- *“I would have liked more detailed information (pamphlet or on-line) describing the lens implant procedure.”*
- *“Perhaps a volunteer corps to provide housing during fitting process? That would reduce costs to those out of town.”*
- *“Have a counselor at the clinic available for patients if they need a resource person to talk to during treatment”.*
- *“More follow-up after services are completed.”*
- *“...possibly behavioral medicine support, although I would be reluctant to rock the boat. Being a behavioral medicine psychologist, it would require a special person.”*
- *“More financial aid. I have decent health insurance but it doesn’t cover my Scleral lens or the cost associated with getting to Boston and food and lodging.”*
- *“I would like to see their facilities more accessible. I was frustrated when I tried to contact <a BFS partner clinic> for a follow up visit for my son. They were rude, and not very helpful. Not at all what I expected. I would fly back to Boston before I visited them even though I live <close by>.”*

More communication and patient/family support services

More than 50 of you offered feedback requesting more/better communication and additional supports you would like to see for patients and families including:

- Peer networking and support groups
- 1-on-1 patient and family peer support
- 1-on-1 consultations with doctors
- More educational materials and access to specialized products

- A regular newsletter or listserv and updated website with more information.
- Follow-up care after fittings with more regular communication and support
- More financial assistance offered to a broader range of people
- Specialist support services such as a counselor/therapist, behavioral medicine specialist, etc.
- Housing support- affordable place to stay, a hostel, peer hospitality services, dorms, etc.
- More transportation support including continued coordination with Angel Flights
- Easy and automated ways to make financial contributions
- Support services and customer service provided at satellite clinics that are comparable to those in Needham

The capacity to serve more patients through additional clinic sites, increased visibility, education and outreach.

When asked about desired improvements you collectively named more than 40 cities, states and countries where you would like to see BFS expand where treatment is offered. Many of you also spoke to the lack of education and awareness within the medical community about this treatment approach in general and BFS in particular. Specific comments include:

- *“I wish more patients knew about BFS. I wish more ophthalmologists and corneal surgeons knew about BFS as well. Specialists tend to be entirely focused in their area, often unaware of alternative solutions.”*
- *“I notice very few people seem to know what BFS can do for sight. I am a professional working in Boston and many people have no idea of your work.”*
- *“Yeah-- EXPAND to other States beyond Boston, Massachusetts...like Ann Arbor, Michigan; Houston, Texas; as well as somewhere on the West Coast like Sacramento, California.”*
- *“I just wish more people knew about BFS and the use of scleral lenses, particularly ophthalmologists so that they would recommend the lenses at a much earlier stage in treatment. I honestly think every major hospital in the US and Canada performing bone marrow transplants should have more knowledge, better access to this institution. Even a BFS Ambassador - a nurse practitioner, so that nobody has to endure the pain, discomfort and reduction in quality of life due to severely dry eyes when there are solutions available.”*

Other feedback

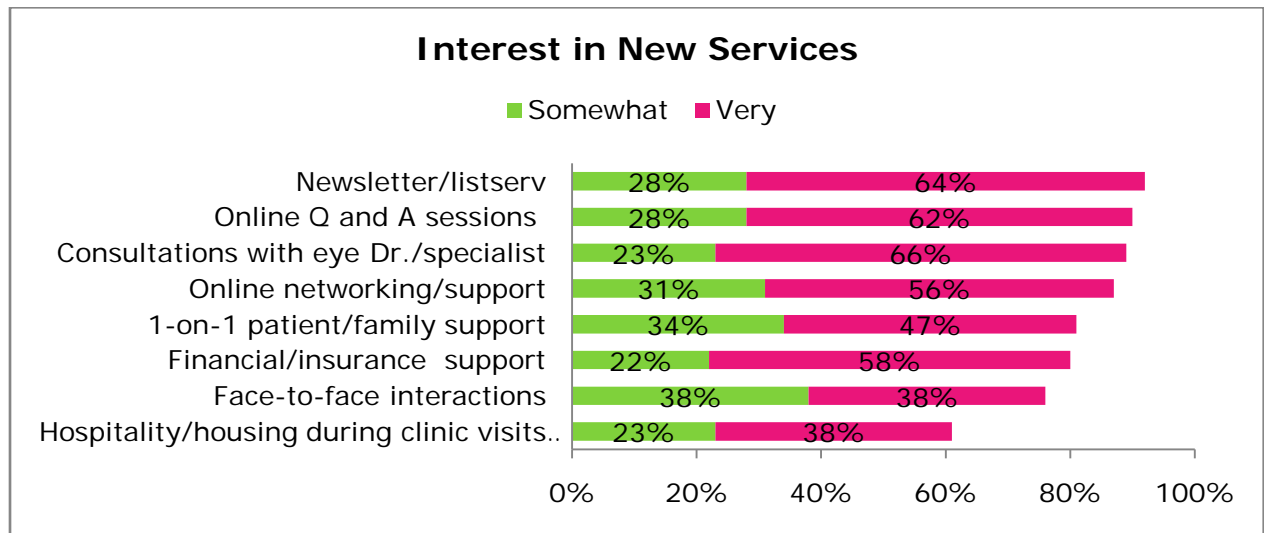
Other feedback expressed by a smaller number of you (less than 10%) includes:

- Requested improvements to the lens surface/coverings to address mucus buildup
- Making the insurance, financial aid and billing process clearer, smoother and more professional

- Allow patients to come to BFS without referrals from eye specialists or provide consults/referrals at clinic sites

SECTION V: DESIRED NEEDS AND ADDITIONAL SUPPORTS

BFS is considering developing a number of additional supports and services for their community. To better understand your wants and needs, the survey provided a list of different types of patient services and supports and asked you to tell us a how likely it was that you or your family members would have used them if they were available to you. This is how you responded:

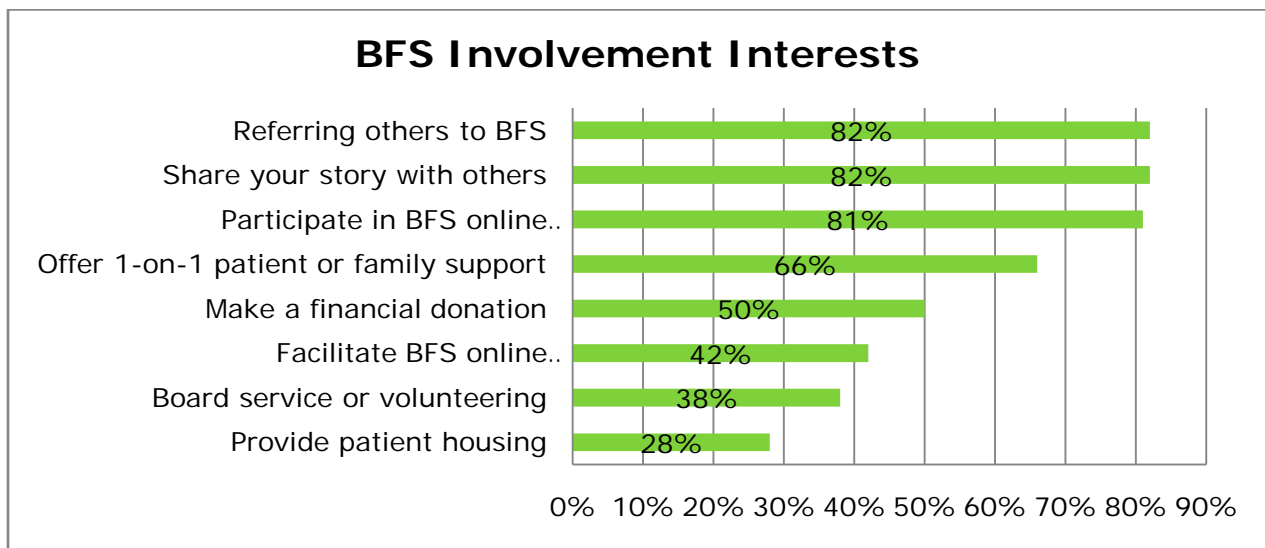


Additional suggestions or requests for support included:

- Opportunities for new or interested patients to speak with a current BFS patient before coming for a consult or fitting
- Group support meetings, networking and “meet and greets”
- Child care help during clinic visits (either on-site at the clinic or financial help for home care while parent’s are traveling)
- Transportation assistance to get to and from clinic visits (reduced cost flights or car rides, transportation vouchers, care services, ride shares, etc.)
- Help finding and financing computer assistive devices such as screen magnifiers, voice recognition software, Braille readers, large-print keyboards, and/or speech synthesizers
- Group buying negotiated for eye products and services
- Notice of technical and medical advances coming in the next few years and new products available

- Identification of manufacturers that would offer assistance overseas and during travel –i.e. providing the new barrel scleral case
- Legal services for government disability
- Outreach and support for people living outside of the United States
- Opportunities for regular email communication with BFS staff/doctors

The survey also asked the 618 of you who are at least “somewhat familiar” with BFS, including current and former patients, if you were interested in being more involved with BFS than you are now. Four hundred eighty of you (79%) responded “yes” (26%) or “maybe but I am not sure how” (53%). Among the possible ways to become more involved respondents reported having “some” or “significant” interest in the following:



Over 60 of you used the comment section to offer other kinds of support that were not included in the survey. Suggestions included:

- Organizing/hosting a fundraising event
- Providing hospitality (housing, food, transportation, etc.) for patients at new partner clinic sites
- Presenting at a professional conference or speaking to local community or professional groups
- Teaching meditation to others affected by eye difficulties
- Volunteering professional skills- technological, medical, writing/editing, mental health, etc.
- Providing information and outreach for patients abroad

Please note: The numbers above do not include the 311 of you who were not asked this question because you indicated you were not at all familiar with BFS.

APPENDICES

I: ADDITIONAL SURVEY DATA

Click here to view [additional survey data](#) including more about:

- Survey Respondents
- Corneal Disease Diagnoses and Underlying Conditions
- Treatments
- Social Networking Sites and Tools
- Desired Needs and Additional Supports

II: SURVEY QUESTIONS

Click here to view the [Boston Foundation for Sight Survey](#).