

seoletining disease Seshuging the grant of the gran

dry eye foundation

a 501(c)(3) nonprofit organization

2022 Annual Report

I used to be an artist and photographer I got lasik and then it was all I keep my house dark. I can't and I had to give that up.

over for comfortable/easy eyes. enjoy sitting near a window.

My problem is sudden onset dry eye pain, shooting pains that make it impossible to drive or function. I use drops, take ibuprofen, use compresses until it finally, and just as mysteriously stops.

I retired fully when I was 66. I would have continued to work (as a nurse) part time if it weren't for my eyes. Not working has also had an impact on my feeling of self worth and mental health.

I am so self conscious that activities I used to enjoy have become something I dread. I have become dependent on others and I feel I have no control over my life anymore because of DED. I cannot drive more than a few miles. I prefer to have my husband drive me to and pick me up at the gym. It has greatly affected my feeling of independence and self worth.

I'm tired of people looking at me as if I smoke pot because of my dry eye symptoms so I just don't go out in public unless I have to. Feel guilty if I express my pain. Try to fake it most of the time. Feel paranoid about people being sick of hearing about it. Don't think anyone I know can really relate to this.

I feel left out of life.

Email after email, message after message. Work is beginning to pile up, and it has never been this way.

My family doesn't understand why I can't fly out to see them. People don't understand why I can't go out to dinner or social gatherings...It's gotten to the point where I don't get invited. I don't like to make new friends because I don't have the ability to maintain the friendship. I've even quit going to church because of the forced air. I'm very sad about this. Thankfully, I have a supportive husband.

I feel like most doctors think I am over-reacting and I feel stupid when talking to them.

It is extremely difficult to find a Doctor that is knowledgeable in dry eye. It is a very lonely disease. I feel helpless dealing with it most of the time. My family and friends do not understand the pain.

I can't afford to throw any more of my family's money away for nothing. I experience terrible anxiety at the thought of even going to another doctor and having my pain minimized. I always feel sick at my stomach when I leave a doctor's office; they make me feel worthless and ignored.

"I have patients who are going blind. All you have is dry eye. It's not that big of a deal. You should consider seeing a mental health professional. I'm a professor in a prestigious medical school, don't you think I would have heard of corneal neuralgia if it actually existed?"

I just do not feel that any doctor truly understands what it's like to live with dry eye. The pain and discomfort I experience every single second of the day. Until I found my current doctors, I thought there was no hope. People need to keep looking until they find a knowledgeable doctor. Most doctors don't want to deal with a patient as complicated as me. Had to refinance last year to get money for sclerals and treatments.

I have spent thousands of dollars on this in the past year and I made a good salary. What the hell is someone supposed to do who is making less or supporting a family? It's insane how much this costs and so little of it is covered by insurance.

I'm feeling ambivalent. Everything I try is just "more stuff." We don't take vacations. I had to retire due Isn't there something that just works? What am I missing? to dry eye, but my costs are still the same.

I am a pretty positive person, but this condition has definitely been trying. At times it is a lifestyle adjustment that I am just not ready to accept. I want to be active and do the things I always used to do. And I hate to have my kids see that Mom is always "eye tired".

The former Dry Eye Zone blog was a lifesaver to me during this time of deep depression. It allowed me to realize that others are facing similar trials and tribulations and it allowed me to learn about techniques other people were trying. For example, it was here I realized how beneficial moisture goggles could be. They make the day bearable.

I am now in my 70's. I lead a normal life, normal within the limits of someone who will always have dry eyes. There is no cure, but there is help.

When it comes down to it, what am I going to do with what I've been given? Will I see it as defeating or can I see it as potential to grow? Every hard thing a person is given in life is an opportunity for a choice. I'm of the belief that beauty can be made from ashes as I allow God room to create it and I want to live my life reframed with that perspective.

Dry eye sucks. I have a hard time accepting my new normal. I have had to go on anxiety medication due to my dry eye and eye pain I've had in the past 6 months. I have improved since I was at my worst and am grateful to be able to manage my pain better, but I worry about my future.

I have been on the dry eye journey for 40+ years and, thankfully, dry eye treatments have come a very long way.

I'm good! I have what works for me! Or at any rate I feel ever so hopeful about the next thing on my list!

I have noticed that my pain increases whenever my nervous system is jacked up. I am slowly learning to take cues from my eye pain when to take a deep breath, a walk, or a break.

Scleral lenses gave me my life back.

To anyone that is just starting this process, I guess having patience is a big key. There is no immediate answer or relief solution, as everyone is different. Just know all of the components of the disease when you go into it and hope for one of the remedies to bring some relief!! And I continually hope for new medical solutions.

I feel like I know what to do every day. I feel like I MAY have a path to being better. I have hope that I still have options.

My recommendation is to keep a journal of what treatments you are using and find a doctor who will actually read and listen about the pain you are suffering. Never give up—there is a doctor out there who probably has the answer for you.

After years of pain, misery, depression and potentially losing everything professionally and mentally, somehow I made it. I rock my coke bottle glasses, wear no makeup, and bounced back to an amazing promotion and maintain the position in front of a computer 8 plus hours per day.

I am empowered, well educated on my options and I have tried everything. I have a plan and am confident in my strategies. But my eyes still hurt every day.

My dry eye issue put me through hell, but in a way it made me a better person too. I still have some better eye and mental health days and some worse but I know I am not alone.

Best advice I got here:

"take one day, one hour, even one minute at a time" and

"don't believe everything you think" and "even when things don't get better, WE get better."

Collected quotes from dryeyestories.com and mydryeyedata.org.

elevating patient voices

When nobody understands

(It's not about "dry eye!")

Ocular Surface Disease

Ocular Surface Pain





create multiple challenges









which intensify the longer my needs aren't met.

My eyes are bothering me so much

"I have a real problem."

It's really affecting my life

I see doctors and I try things

No one seems to understand

"I take steps to solve it."

work as expected

Treatments don't "It's hard and it takes a long time."

It's really hard to know what to do next

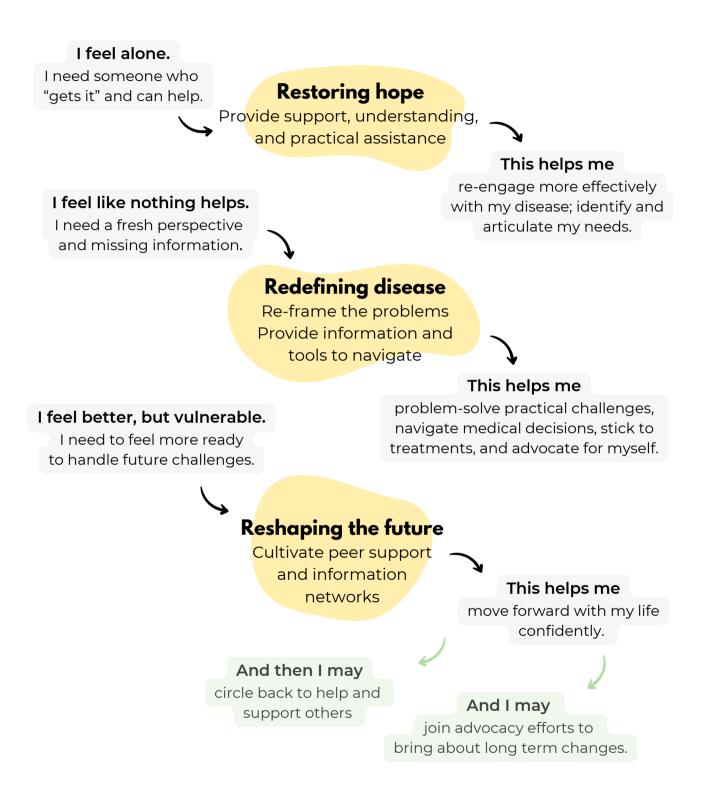
How can "dry eye" be this hard to solve?

"This leaves me confused, anxious, I'm losing hope depressed, and discouraged."

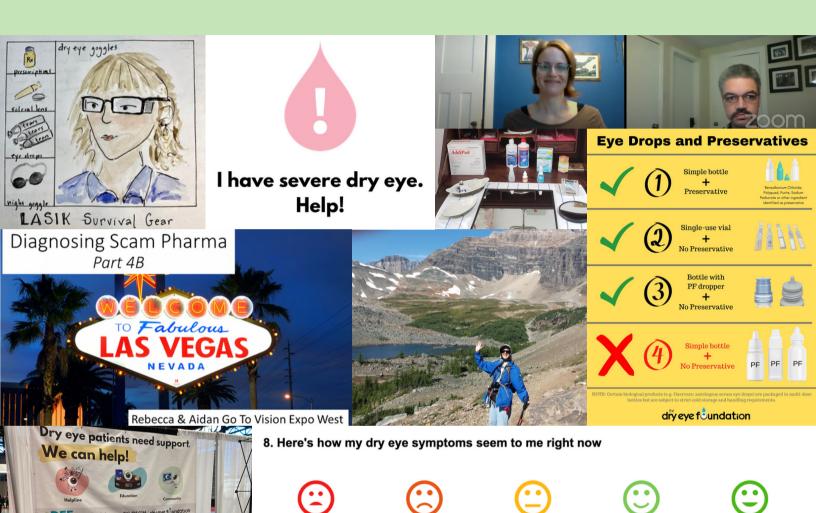
Doctors don't seem to know enough



We step in to break the pattern



Programs



"Dry eye disease is so isolating but I realize I am not alone. The Dry Eye Foundation is doing critical work to support and advocate for patients like me."

-Molly

Hard.

Having a really hard

time.

So-so.

Ups and downs.

Stressing, but not

completely miserable.

Out of control.

This has completely

taken over my life.

Totally doable.

My symptoms are

pretty low grade these

days and what I have,

I can control pretty easily.

Manageable.

I have significant

symptoms, but I can

cope and I have some

tools

Community Support Services

myDEF

New in 2022

 Portal for member profiles, event calendar, donations, membership, and volunteering



Zoom Groups

Since 2021

- >100 meetings in 2022
- Support groups include Dry Eye; UK Dry Eye; Millennials with Dry Eye; Dry Eye and Mental Health: Scleral Lens Users

DryEyeStories.com

Since 2018

- 34 featured stories tagged by disease, topic
- Stories from writers at all stages of their dry eye journey ("crisis" to "remission")

Facebook Groups

Since 2014

- DryEyeTalk
- MyBigFatScleralLens (patients and optometrists)
- Additional specialty groups
- Moderated for safety and content

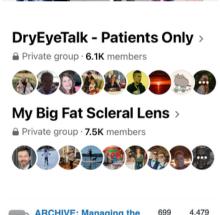
Forums (DryEyeZone)

Since 2005 (Functions mostly as archive now)

- ~120,000 posts
- ~10,000 members









Dry Eye Helpline

What it is

An individual counseling and support service established in 2020 as an adjunct to DEF's multi-channel peer support system.



Why it's needed

Our ocular surface disease community struggles with a complex, poorly understood disease burden.

We need orientation, practical information and empathetic support from experienced peers to help us navigate our many medical, practical, financial and emotional challenges with confidence.

How it works

We schedule phone calls or Zoom sessions. Intake sessions are typically 60 minutes and follow-ups typically 15 to 30 minutes.

Depending on a client's specific needs, there may be a single session, a series of sessions, or ongoing biweekly or monthly sessions. Services often include follow-up research and emails. Afterwords, we check in by phone or email.

>200 clients served in 2022

Phone, text & email

DEF is available from 8am to 4pm weekdays (Pacific time) on our 800 number. Our community has many information needs and we are always ready to help.

"I see so many people with facial paralysis that suffer every day because of pain in their non-blinking eye. Rebecca's experience and her deep understanding of dry eye issues, and eye pain, is priceless(!) and can really help so many people from the facial paralysis community"

Dry Eye Happy Hour

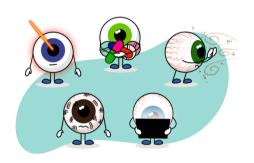


We launched Dry Eye Happy Hour in the heart of the pandemic to help isolated patients feel more connected

Dry Eye Happy Hour sessions are patient panel discussions in Zoom webinar format on topics related to navigating the practical aspects of living with ocular surface diseases. Each panel is a group of four to six patients. After the main discussion they field questions from attendees.







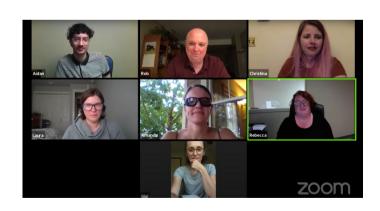
Why Are We Dry?



Overnight Dry Eye

Additional Dry Eye Happy Hour topics included:

- Facing our Dry Eye Fears
- Finding a Doctor
- Dry Eye at Work
- Elective Eye Surgeries
- Dry Eye Under 30
- Plus more



In all, we produced 17 sessions.

We are planning to re-start this program in 2023 due to its ongoing popularity.

Raising awareness

How did you find us?

YouTube? Reddit? Searching on Google? Facebook? A podcast? From your doctor? From a friend?

Perhaps you watched one of our YouTube recordings and decided to get in touch with the Helpline or to join a group. But many people tell us that they wish they'd heard about us sooner, and a common theme is people wishing their doctor had referred them to us for support.

Expanding our reach

In 2022, we began an literature program to put patient brochures in the hands of eye care professionals. DEF exhibited at two professional meetings, networked with doctors and industry, and distributed 1,200 patient brochures.

Other outreach programs have included program-specific Google ads, email newsletters, livestreams, and social media posts, as time allows.



American Academy of Ophthalmology Annual Meeting October 2022 Chicago, IL



Education

Key topics

Orientation

Ocular Surface Disease

Emotional

Depression, anxiety, loss and grief, constructing support systems

Ocular Surface Pain

Functional/practical

Computer use; driving; outdoor activities; overnight dry eye; communication strategies

Medical

Assembling a medical team; appointment prep; understanding diagnosis; treatment options; OTC products questions; product safety, recalls and shortages

Financial

Insurance; patient assistance programs; disability; employment issues

Education channels

- Mailing lists
- Webinars
- Helpline
- Zoom groups
- Facebook groups
- YouTube
- Websites (pictured)
- Special projects in partnership with doctors, industry or advocacy groups



Research

Program goals:

- 1. Document the experiences of our community through our own research.
- 2. Engage academic and industry research in the topics that are the most important to us.

Community survey

Dry Eye Disease and Me





Topics:

- Symptoms (12 questions)
- Qualify of Life (15 questions)
- Causes, Co-morbidities, Context & Clues (21 questions)
- Remedies & Treatments (38 questions)
- Experiences with Doctors (10 questions)
- Finances (10 questions)

Summary data available at mydryeyedata.org. Examples from survey responses on pages 2-3. Full report expected in 2H2023.

Example of recent research contribution:

Caffery et al, 9/2022: Patient perspectives on dry eye disease and chronic ocular surface pain: Insights from a virtual community-moderated dialogue, European Journal of Ophthalmology.

Advocacy

What advocacy means to us

Advocacy weaves its way through all of DEF's community service, education and research programs. We work to equip individuals to advocate for themselves, and we work to elevate the patient voice in eye care and in industry. In addition, from time to time, we choose to engage a specific overlooked problem or need, particularly those related to patient safety. Here's an example.

Spotlight: Biologic Eye Drops

In early 2022, we became aware that commercialized biologic eye drops were being bottled unsafely, packaged and labeled inadequately, marketed deceptively, and sold illegally. Many doctors were recommending them, unaware of the issues.

We engaged in extensive research, sharing our findings with the Food and Drug Administration. When we understood the timeline for legal enforcement of the many concerning violations, we engaged in an exposé of the manufacturers' actions, impelled to this step by our concern for patient safety. We created a website and began sharing our information with the community, including 28 separate educational presentations prepared by our medical advisor. Since we launched this initiative, the manufacturers have drastically altered their marketing practices and the FDA has published letters to both. This project is ongoing.

Additional developments in the over-the-counter drug space have made it clear that we are in the midst of a rising tide of unscrupulous and incompetent drug manufacturers. Tragic outcomes from eye drops recalled in early 2023 have underscored how high the stakes are for eye drop safety. We are committed to fighting for the safety and integrity of eye drop manufacturing and marketing.

I noticed some red flags right away. The box had no ingredients list. The bottle looked "cheap," with a badly printed, crooked sticker. I was worried about the type of bottle, which has no filter. Despite all this, I used the product, because I trusted my doctor. My symptoms and inflammation started to get worse, and very quickly. The man on the phone [at the company] said that what I was experiencing was normal. I called again after five weeks of progressively getting worse. At no time was I told to call my doctor. -Patient story at biologiceyedrops.org

Funding and Financials

"The knowledge I gained here empowered me to wrestle happiness back from severe lasik induced dry eye. Almost 8.5 years since my lasik procedure I still have severe dry eye, but I am a happy person, a good dad, and a hard and productive worker. This seemed unattainable in the months after my operation and when I was realizing I would likely have to deal with it forever."

-Kevin



Our most memorable donation arrived in the mouth of this camel teapot.

The camel is a tongue-in-cheek reference to dry eye community hyperbole expressing the extent of our desperation: "I would put anything, even camel spit, in my eyes if I thought it would help."

Donors

We are deeply grateful to everyone whose generous support has made the Dry Eye Foundation's programs possible.

Aidan Moore

Amanda Mott

Barrie Rappaport

Beverly Coughlin

Brett Kestenbaum

Brooke Smith

Carol Allison

Catherine Gibson

Cynthia Blattman

Cynthia Edwards

Cynthia Howes

Cynthia Jensen

Dana Schmidt

Dave Villano

David Needs

Deborah Caruso

Denise Cedar

Dennis and Marla Parus

Diana Coble

Diane Jeffery MD

Don Winer

Dry Eye Company

Edy Jablonsky

Elisa Freeman

Fllen Krantz

Ellen R Israel

Eric Dunn

Eric Flasher and Rhonda Baggett

Francine Spindel

Fred Sherman

George W. Potts Jr

Gisela Bailey

Grace Brennan

Hilarie Hauptman

Hilarous Giver Fund

Irving Winer

J Knapp

Jack Bier

Jamie Thayer

"I thank God for this site which has given me strength, hope and good ideas to help live this life with this condition. Thank you!!"

-Tomi

"The dry eye foundation has been a lifeline for me."

-Catherine

Jane Moore

Janet Sternfeld

Jim in Italy

Jim Kyle

Jo Thornton Curtz and Thaddeus Curtz

Joanne Tolles

Joseph Gagan

Josephine Lucciola

Joyce Kilmer

Judie Harchar

Judith Simon

Karen A Nunes

Karen Robinson

Karen Whall

Kathy Pruitt and Mark Collins

Katie Roche

Ken Goldberg

Kenneth Goldberg

Kevin Tulk

Laura Ballenger

Laura Senft

LeAnna MacDonald

Lee Castillo

Linda Howey

Linda Lawson

Lisa Abney

Lisa Berlin

Lorelei Sontag

Lori Tyler

Lucille Kaplan

Lynn Grotsky

Marcy Plotnick

Margaret Copley

Mariam Morley

Marla Menning

Marlesa Roney

Marta Harshbarger

Marti Partridge

Mary Bowman

Mary Cota

Mary Porter

Michael Karman

Michael Shore

Michelle Galgoci

Michelle Hollingshead

Mimi Hall

Molly Chidsey

Nancy B. Pollak

Nancy Costantini

Nancy Klibanoff

Neil Williams

Nelda Tawse

Nikolai Smirnow

Pam Chakalos

Patricia Beuke

Patricia Kanter

Patty Witte

Penny Purkerson

Peter Peregrino

Ping Zhang

Rachel Lewine

Rebecca Fagenson

Rebecca Petris

Rich Rodriguez

Rick Hall

Rikki Tooker

Roger Newton

Ronni Dealy

Rosalyn Owen

S A Manning

Sandi Dambrosio

Sarah Croker

ScienceBased Health

Shelley Patey

Sohaib Ashraf

Stacey Cruz

Steve Pesner

Susan Gair

Tanja Harrell

Terry Feldmann

Tomi Ryan

Valerie Mead

Virginia Harmon

Anonymous donors

Amazon Smile customers

Dry Eye Shop customers

Facebook Fundraiser donors

Optometrists participating in the Eyes On Dry Eye conference

"The Dry Eye Foundation provides various useful services to all. Their educational yet personal approach is appreciated and sheds light on this topic that I believe is not widely known or discussed enough."

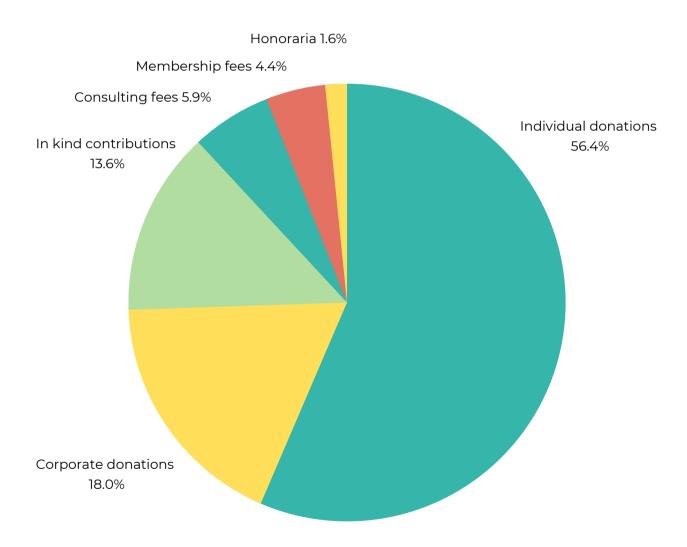
"Thank you for your dedication to science and to helping people suffering with dry eye disease."

-Judith

Fundraising

\$51,975 raised in 2022

The majority of our funding consists of donations from individuals in the ocular surface disease community. Additional sources of income include donations from companies; honoraria for speaking events; fees from consulting about the ocular surface patient journey; in-kind donations of rent, utilities and office expenses; and (new in 2022) membership fees.



2018 to 2022 Fundraising

	2019	2020	2021	2022
Individual donations # of donors*	\$18,532 52 donors	\$17,172 50 donors	\$25,341 41 donors	\$29,325 90 donors
Corporate donations	\$1,018	\$2,718	\$240	\$9,381
In-kind donations**	-	-	\$6,953	\$7,061
Honoraria, consulting, other	-	-	\$400	\$3,928
Membership fees	-	-	-	\$2,280
Total raised	\$19,550	\$19,890	\$32,934	\$51,975

^{*}Does not include individuals who contributed to Facebook fundraisers

"The Foundation is filling a void for many people suffering from the physical and emotional effects of this chronic condition."

^{**}Rent/office expenses provided in-kind in 2019 and 2020 but were not tracked

Financial activity

Cashflow 2018 to 2022

As a small start-up organization staffed by volunteers, we kept our costs very low in the initial years, and our largest expenses were technology costs and travel costs to attend medical conferences. In 2022, our program marketing expenses increased substantially as we began exhibiting at optometry and ophthalmology conferences. The biggest change we anticipate in 2023 is increased payroll spending.

	2019	2020	2021	2022
Beginning cash	\$900	\$13,588	\$18,378	\$27,091
Revenue	\$19,550	\$19,890	\$32,934	\$51,975
Expenses*	\$6,862 42% admin 58% programs	\$15,100 20% admin 80% programs	\$24,221 16% admin 84% programs	\$60,684 13% admin 87% programs
Net cashflow	\$12,688	\$4,790	\$8,713	(\$8,709)
Ending cash	\$13,588	\$18,378	\$27,091	\$18,382

^{*}Cash expenses (excludes rent/office expenses provided in-kind)

2022 Financial Statements

(\$ 8,709)

Financial Activity

Statement of Financial Position

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Donations	45,767
Membership fees	2,280
Consulting, honoraria	3,928
Total revenue	\$ 51,975
EXPENSES	
Bank charges & fees	90
Consulting	500
Fundraising	25
Insurance	1,062
Legal	391
Marketing	16,831
Merchant fees	561
Miscellaneous	132
Office expenses	2,181
Payroll	13,785
Rent & lease	3,924
Taxes & Licenses	462
Technology	5,560
Travel & events	15,179
Total expenses	\$ 60,683

Net cashflow

ASSETS

Current Assets: Bank accounts	18,380
Total assets	\$ 18,380
LIABILITIES AND EQUITY	
Liabilities	0
Total Liabilities	0
Equity	0
Unrestricted Net Assets	27,089
Net Revenue	(8,709)
Total Equity	18,380
Total liabilities and assets	\$ 18,380

What's next?

Things in progress or scheduled in 2023

On the administrative front, we are:

- engaging a full-time employee for the first time;
- diversifying our funding sources;
- mastering our new nonprofit software systems; and
- planning for a future administrative assistant

On the programs front, we are:

- engaging in safety education initiatives, including new website eyedropsafety.org;
- launching our new website for prospective and current scleral lens users, mybigfatsclerallens.com;
- reviving Dry Eye Happy Hour and starting new Zoom groups;
- participating in webinars;
- collaborating with other nonprofits; and
- expanding our fledgling membership program

On the awareness front, we are:

- exhibiting at three national conferences,
- expanding our literature distribution program, and
- expanding our digital marketing

Things in blueprints

Our dream resource library for patients and presentation library for eye doctors.

Things imagined

Imagine a future where, after your eye doctor appointment, you sit down with (or have a telehealth appointment with) an Ocular Surface Pain Technician. This technician has a standard protocol to review and score your current disease burden in terms of functional, financial, and emotional impact, and to identify any specific problem areas (Computer use? for reasonable accommodations at work? Driving? Out of pocket drug costs? Anxiety about travel?) They have a library of information and resource sheets to draw from for every need that is discussed.

What can YOU imagine for the future of dry eye?

Board of Directors



Sandra M. Brown, MD (Concord, NC)

Dr. Brown is an ophthalmologist focusing on pediatric ophthalmology, adult strabismus, neuro-ophthalmology and forensic ophthalmology. She serves as DEF's medical advisor.

Cynthia C. Edwards, MSN, RN (Pittsburgh, PA)

Cindy had a 40-year healthcare career as an RN. She has personal experience with glaucoma, corneal dystrophy, and OSD. She serves as DEF's Secretary.





Aidan S. Moore (Poulsbo, WA)

Aidan has worked in the dry eye field for the past seven years. He is a DEF co-founder and has previously served as Secretary and Treasurer. He graduated from Pomona College in 2020.

Amanda L. Mott (Madison, WI)

Amanda is an executive policy and budget analyst for the State of Wisconsin, and a longtime dry eye patient. She joined DEF's Board of Directors in 2019 and serves as its Vice President.





Rebecca E. Petris (Poulsbo, WA)

Rebecca has dry eye, neuropathic pain from LASIK, and founded Dry Eye Zone in 2005 (predecessor to DEF). Rebecca is a DEF cofounder, serving as President since 2018.

In memoriam: Rosalyn Owen 1940-2022 (Poulsbo, WA)

Roz held senior positions at a large foundation for decades. In retirement, she continued reviewing grants for community and governmental organizations and mentored local nonprofits. She was a DEF co-founder and Treasurer from 2018 to 2020.



From 2018-2022, DEF's day to day operations have been carried out on a volunteer basis by its Directors. The following individuals have also served on DEF's board: Debbie Auday (Santa Barbara, CA), 2022; Roger Newton (Bremerton, WA), 2019-2021.

Postscript: Values

While drafting this report, we found ourselves prowling around obscure corners of DEF's main website and stumbled across this list of values (circa 2019-2020). We took the opportunity to revisit our early intentions for the Foundation's values.



COMPASSIONATE SERVICE: We care deeply. Mmm hmm. that's why we're here



RELEVANCE: We get it, listen well, ask the right questions, and do things that are actually helpful. Oooh yeah, \$\frac{1}{2} \text{ just wait'} \text{ they see the DEDAM report}



SMARTS: Analysis consistently on point with periodic strokes of genius.

Who us, smug?



HOLISM: None of us is a disembodied pair of eyeballs. We are each a unique dry eye context.

Yeah DEDAM was a big part of establishing that



ACCESSIBILITY: People need to be able to find us. Did our best on a tight budget

This year's industry \$\$ should help



UNCONVENTIONALITY: Because the expected is redundant.

Nailed it



HUMILITY: We don't know everything, and it's not all about us.

Don't forget to run a brag check before this goes to the printers



A DASH OF FUN: Dry eye is depressing. Let's spice things up a little.

Yeah sometimes we take ourselves too seriously



TRANSPARENCY: We want our community and its supporters to know all about what we are doing, how, when, and why, and what it's costing.

FINALLY! That's what this report is all about! That, and to thank our supporters!!

How are we doing? Get in touch and share your thoughts about our first Annual Report!





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