



ApoE4.Info

Annual Report

2018

ApoE4.Info, Inc. closed out its fourth year leading, serving, and strengthening understanding of the APOE- ϵ 4 gene. As carriers of the gene most closely related to the common form of Alzheimer's, we seriously undertake our role as the voice of those at risk. We continued to evolve our services to best meet the needs of our members, we actively worked with the research community searching for strategies to mitigate the effects of APOE- ϵ 4, and we continue to educate the public at large by leading an advocacy movement for our population.



A word from our President

Hello Friends-

Another year has flown by and the seeds from our ApoE4.Info project continue to scatter and grow. When I see the influence our community is having on the outside world, I'm filled with a sense of both awe and gratitude. As an ApoE4 homozygote, I keenly recall the dark days when I first learned of my high genetic risk for Alzheimer's. It was almost seven years ago and I was already having concerns with my cognition at that time. I was unable to find any information about what I could do to mitigate that risk. When I sought help from my neurologist, he said: "Good luck with that." Seriously. I learned that Alzheimer's was incurable, untreatable, progressive and fatal. The worst part, I was told that it couldn't be prevented. Instinctively, I knew that was wrong. There had to be **something** I could do; some lifestyle or diet change that could tip the odds in my favor.

Many of you shared that same quest for information and had similar fears. That sense of purpose brought us together on the 23andMe forums where we began forming our community and later led us to create our own non-profit where we could better focus our efforts. By working together, we are making progress. I'm confident that I'm on a path towards healing and I'm full of gratitude to be taking this journey with each of you.

ApoE4.Info is a 501(c)(3) tax-exempt public charity

Our Mission:

ApoE4.info, Inc. is dedicated to understanding the APOE-ε4 gene and how it impacts health. We do this by:

- *providing basic information about the APOE-ε4 gene*
- *running an active forum and Facebook page*
- *acting as a contact point for anyone interested in the APOE-ε4 gene*
- *pursuing research about the APOE-ε4 allele to mitigate related negative health effects including but not limited to Alzheimer's disease and cardiovascular disease*
- *connecting researchers and carriers of the gene*
- *organizing regular APOE-ε4 Conferences*
- *working with the media to inform and educate health professionals and the public about the APOE-ε4 gene*



I'm especially proud that no ApoE4 carrier ever has to navigate this knowledge alone like many of us did... until we found one another. Thanks to our ongoing partnership with the Functional Medicine Coaching Academy (FMCA), we continue to have a rotating group of FMCA certified health coaches who are working as interns on our forum. Along with our senior support staff, they greet and offer support to every new member. Each of our interns has also completed the *Reversing Cognitive Decline* advanced certificate offered by the Institute for Functional Medicine. They are available to work with any member who feels the need for one-on-one support. You can find a list of [health coaches](#) and ApoE4-aware health care [practitioners](#) on our wiki. I'm very grateful to our all-volunteer team - the interns and senior staff who welcome new members and the leadership duo, **slacker** and **JML**, who recruit, train, and manage the team.

To deepen community ties and create opportunities to learn, this year we launched our virtual Meet-up Forum allowing members the opportunity to gather by videoconference. By conducting a poll, we learned that our members wanted to be able to meet-up without necessarily having to fork out the expense of having to travel. So far, we've had members gather to discuss and learn a variety of skills; everything from how to ferment vegetables for gut health to learning Qigong, a meditation through movement practice, to reduce stress. Anyone who wants to launch a meet-up can make an announcement [here](#).

I was humbled when Dr. Dale Bredesen, author of the New York Times bestseller *The End of Alzheimer's*, asked me to help him with his follow-up book early this year. This new book will feature survivor's stories, including several from our community, and include a handbook on how to optimize your cognition at any age. Dr. Bredesen recognizes that our community is ground zero for living a brain healthy lifestyle. In the book, we take a deep dive into diet, exercise, stress reduction, sleep optimization, cognitive enhancements, supplements, toxins, and much more. Dr. Bredesen wants to make his protocol affordable and broadly available to all. It's been an enormous labor of love



to distill our community's combined wisdom into the handbook. The book will be published by Avery, a division of Random House, and be available later this summer.

In the spring of this year, the Department of Defense's Peer Reviewed Alzheimer's Research Program (PRARP) sought input from our community regarding PRARP's research priorities. Two of our senior members, **NF52** and **Fiver**, volunteered to help and were welcomed onto the scientific review panel as customer advocates with full voting rights. They traveled to Baltimore in December and helped to allocate \$15 million appropriated for Alzheimer's research by Congress for fiscal year 2018. We join Colonel Stephen J. Dalal, Director of the Congressionally Directed Medical Research Program, in thanking them for sharing their perspectives and expertise.

Some of our members are participating in the Generation Studies I & II that are evaluating the efficacy of several amyloid modulating drugs in a pre-symptomatic population. Novartis asked us for advice regarding their participant support policies and procedures. They were particularly concerned with navigating the tricky terrain surrounding revelation of genetic status. I joined them as a member of a patient advisory panel in New Jersey

this past summer. I was impressed with their acknowledgement that lifestyle is our current best defense, their commitment to finding a pharmaceutical cure, and their sensitivity to our concerns.

Last fall, amidst the California wildfires, I spoke about our ApoE4.Info project to an international audience at the World Alliance Forum in San Francisco. The event featured healthcare gamechangers - innovators in science, policy and business for healthy aging. I was particularly inspired to learn how Japan promotes health at ALL ages for the greater good. Japan leads globally in longevity and healthspan, so Japanese seniors enjoy life options that are inaccessible to many age peers in other nations. Japan's example inspires me to promote similar public health policies in the United States and elsewhere. Our best chance of avoiding Alzheimer's disease involves practicing a healthy lifestyle as early as possible. Who better than ApoE4.Info to spread that message?

Because drugs focused on amyloid and tau continue to fail, some pharmaceutical companies have withdrawn from Alzheimer's research altogether. As profit driven organizations, they lack the incentive to study dietary and lifestyle interventions, supplements, and off-patent drugs despite great apparent potential. Fortunately, the interest in our community from academic and entrepreneurial

scientists continues. Working with our newly established Science Advisory Committee, we are developing a number of opportunities. Our likely first initiative will offer a framework for members to conduct their own N-of-1 trials against a rich set of 300+ biomarkers. The multi-year project will also offer participants a promising intervention after the first year as an option. As we gain experience with and establish infrastructure supporting the organization and aggregation of our members' individual trials, we expect our research collaborations to be an ongoing source of ApoE4-specific hypotheses to influence and inspire the scientific community.

I begin this new year so grateful for each of you as I remember the dark days and now feel a tremendous sense of hope. Knowing that each of us is on a similar health journey creates our connection, our community, our *family*. We couldn't have come this far working alone. Huge thanks to every single one of our volunteers and donors. We are an all-volunteer community run solely by your donations. I'm continually humbled by your generosity. Let's keep moving towards greater understanding of the ApoE4 gene so that our children can enjoy robust health free of dementia and cardiovascular disease.

With gratitude-

Julie

“Genes get turned on, turned off, or modified by our environment; what we eat, who we surround ourselves with, and how we lead our lives.”



-Lynne McTaggart, author of

The Intention Experiment: Using Your Thoughts to Change Your Life and the World

Financials

We are an all-volunteer organization. Our work and the subsequent HOPE we provide, wouldn't be possible without the support of many people. But we still have expenses and greatly appreciate all monetary contributions to meet our current expenses and to fund future meet-up plans and research opportunities.

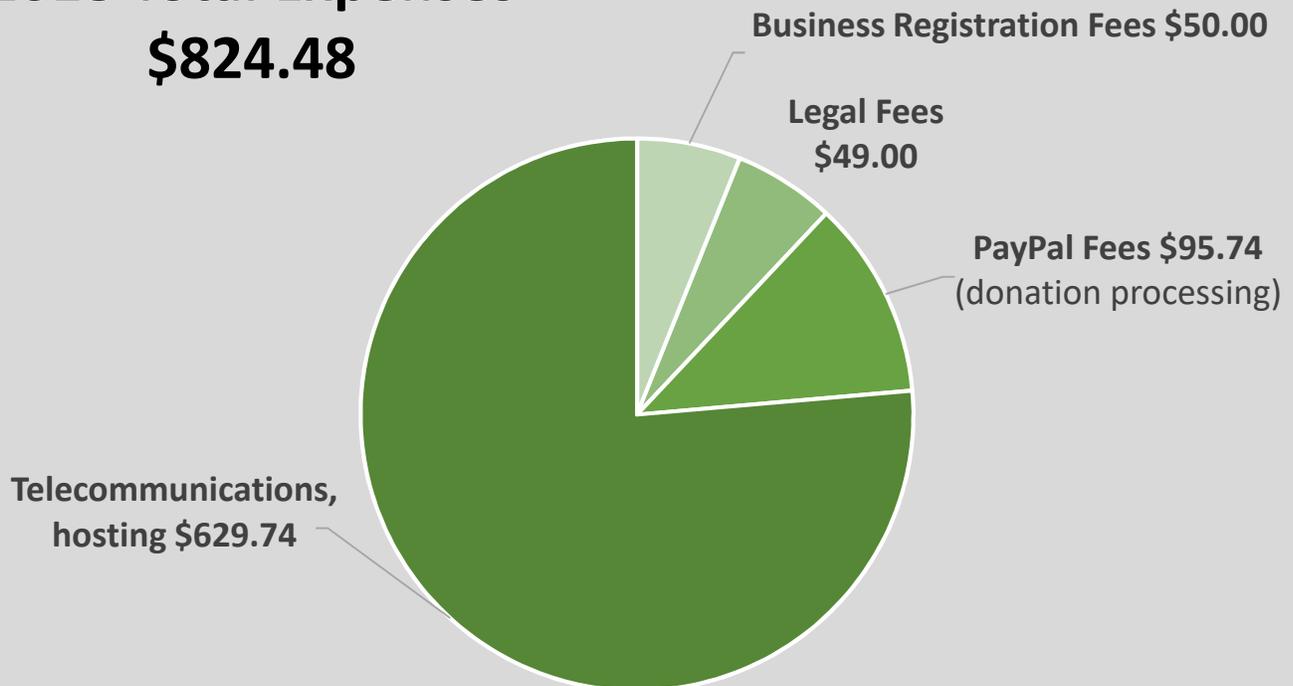
The ApoE4.info website is our primary means of communication and as you can see from the below pie chart, that is where the vast majority of our expenses were dedicated in 2018.

Every Gift Matters!

A BIG thank-you to donors who gave individual contributions and to those who designated **ApoE4.Info Inc** as their [AmazonSmile](#) charity.

2018 Contribution by Type	
Amazon Smile	\$250.53
Forum	\$2,335.00
Other	\$410.00
Total:	\$2,975.53

2018 Total Expenses \$824.48



INCOME AND EXPENSE	
Income	
Corporate Contributions	\$230.53
Individual, Business Contributions	\$2,745.00
Interest-Savings, Short-term CD	\$ 21.87
Total Income	\$2997.40
Expense	
Business Registration Fees	\$5.00
Legal Fees	\$49.00
PayPal Fees (donation processing)	\$95.74
Telecommunications, hosting	\$629.74
Total Expense	\$824.48
Net Income	\$2172.92

