



ApoE4.Info Annual Report 2019

ApoE4.Info, Inc. closed out its fifth 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-

We close out the decade full of HOPE. I'm regularly inspired when I see members of our community, who initially arrive on our virtual doorstep full of anxiety, reporting back several months (or even years) later about their health improvements and subsequent confidence for the future. Almost eight years ago when I first learned of my high risk, there was a wealth of dire scientific predictions for our genotype with zero consensus about how to prevent or mitigate its effects. Thanks to our brave band of citizen scientists working together, *that is changing*. By learning and sharing which strategies move us towards health, we are informing one another and more broadly the larger Alzheimer's community. We are proof that knowledge is power. Knowledge of our ApoE4 status provides the opportunity to begin implementing the dietary and lifestyle changes that can prevent or even mitigate the effects of our high risk allele.


To that end, we're still working behind the scenes with OpenCures to create a longitudinal open-access dataset in which we will share our anthropometrics, multiple biomarkers including metabolomics, with periodic cognitive testing along with a description of our diets and lifestyle strategies. This framework will

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

Our Mission:

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

- *providing basic information about the APOE-ε4 allele*
- *running active forums and a Facebook page*
- *supporting APOE-ε4 carriers and their loved ones*
- *acting as a contact point for anyone interested in the APOE-ε4 allele*
- *exploring ways to mitigate Alzheimer's, cardiovascular, and other diseases to which carriers are more susceptible*
- *connecting researchers and carriers of the allele*
- *organizing ongoing APOE-ε4 meetups*
- *working with the media to inform and educate health professionals and the public about the APOE-ε4 allele and strategies to prevent or delay onset of cognitive decline*



**We may all come on different ships,
but we're in the same boat now**

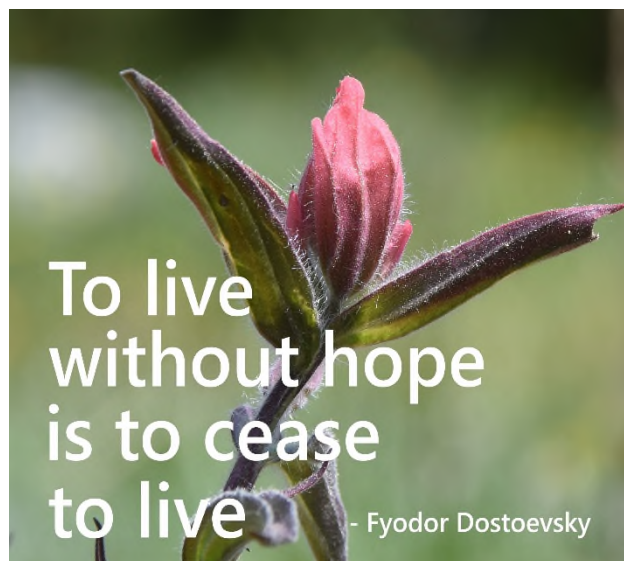
- Martin Luther King

provide an opportunity for participants to conduct self-directed or “action” research (where patients and researchers authentically work together) that will not only inform themselves about how specific strategies affect their health and cognition, but also our community, and the broader scientific community. The metabolomic portion will provide an opportunity for us all to see how specific strategies are affecting us at a cellular level. A member of our community, Emily Cole, PhD, an academic researcher with a focus on action research, has expressed interest in acting as our project manager. We hope to share more information about this project in the coming year.

We continue to connect our members with Alzheimer’s researchers by announcing opportunities to participate in clinical trials. This year, we helped to recruit for several studies including an ApoE4 homozygote gene therapy trial at Weil Cornell. After years of recruiting for the Generation 1 & 2 studies, we were very saddened to learn of its discontinuation in July of this year. Brave members of our community had been generously participating while offering one another support on our site. We are very grateful for their efforts that have culminated in furthering our understanding of the amyloid hypothesis.

Our community continues to receive recognition from Dr. Dale Bredeesen, founding President and CEO, professor Emeritus at the Buck Institute for Research on Aging and author of the New York Times bestselling book *The End of Alzheimer’s*. I’ve been honored to be working with him and his integrative physician wife, Dr. Aida Lasheen Bredeesen, on the sequel to the first book, entitled *The End of Alzheimer’s Program: The First Protocol to Enhance Cognition and Reverse Decline At Any Age*, available August 2020. I was recently humbled to learn that the book will be dedicated to our ApoE4.Info community to acknowledge our pioneering efforts.

This past year, I’ve also accepted a position, as an independent contractor, to serve as the chief health liaison for his new company, Apollo Health where I



serve as a part of their medical team, helping to translate Dr. Bredeesen’s science into clinical practice and then working with the software team to turn that information into health content for subscribers. My contributions to the book and Apollo Health have sprung from my own health journey and experimentation, but also to a large extent, from the combined knowledge of our vibrant community.

The Department of Defense’s Congressionally Directed Medical Research Program’s Peer Reviewed Alzheimer’s Research Program (PRARP) has once again sought input from our community regarding their research priorities. **NF52** once again generously volunteered to help and was welcomed onto the scientific review panel as a consumer advocate with full voting rights and helped to allocate \$15 million appropriated for Alzheimer’s research by Congress for fiscal year 2019. When commenting on serving as a consumer reviewer, **NF52** said “Scientists who evaluate innovative grants on the risk of traumatic brain injury (TBI) for late-onset AD and other dementias are eager to hear the voices of those with TBI and ApoE4. In addition to being a Consumer Reviewer, I was asked to speak to the experiences of our members who have both TBI and ApoE4 at the Plenary Dinner for all PRARP participants. Afterwards, clinicians and researchers asked me to thank the ApoE4.Info community for our hard-won wisdom and our advocacy for high-impact research.”

We join the Congressionally Directed Medical Research Program's director, Colonel Stephen J. Dalal, in thanking **NF52** for sharing her perspective and expertise.

We've expanded our educational outreach mission largely due to the efforts of **Theresa**. She, along with other members, have continued to create novel content for our wiki page, providing ApoE4 specific content for our community and beyond. **Theresa** also joined our [Facebook](#) team in August and dramatically increased the overall community engagement by 112%, thereby increasing awareness of ApoE4 issues and informing a much larger audience.

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. I'm very grateful to our all-volunteer team—the interns and senior staff who welcome new members and the 2019 leadership team, **slacker**, **JML**, and **NF52** who've helped to recruit, train, and manage the team as well as maintain our wiki list of ApoE4-aware health coaches and practitioners to serve as a resource to our members. A special thanks to **slacker**, who's recently

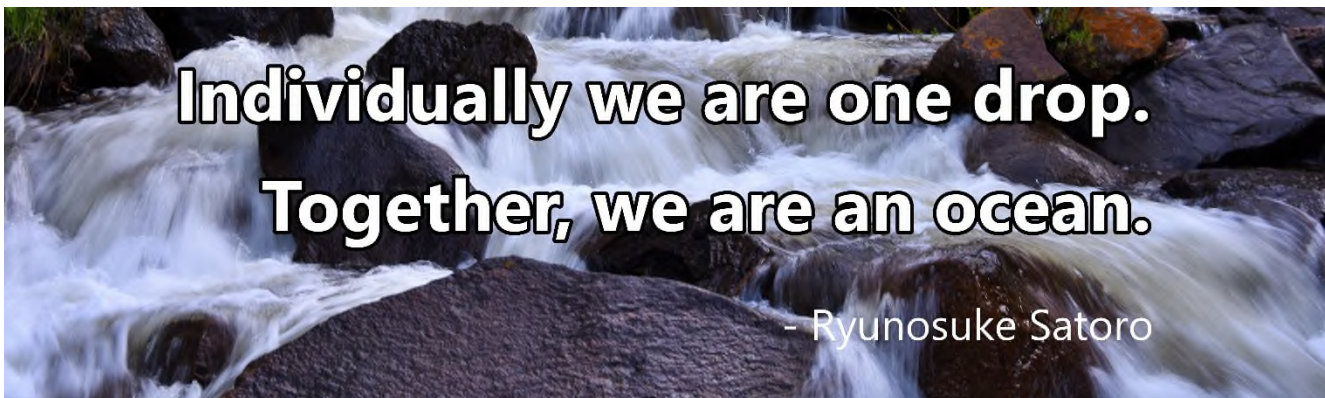
retired from this position, but continues to serve on our support team.

We've worked to deepen community ties by creating opportunities to gather around topics of interest with our Meet-Up forum. Members have traveled to gather in multiple geographic locations around the country, including Northampton, Massachusetts; San Raphael, California; Indianapolis, Indiana, Chicago, Illinois, and Seattle, Washington. Additionally, we had a large team meet via videoconference to discuss the coordination of an Alzheimer's prevention initiative.

I begin this new year so grateful for each of you. 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 especially our tireless board of directors comprised of Theresa Braymer, vice president; Marc Rouleau, treasurer; George Newman, secretary; Andrea Steinberg, M.D., director upon whose advice and counsel I continue to lean on. 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 Gregory, President



Financials

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

This past year the majority of our expenses were dedicated to sharing information and research: our apoe4.info website and our teleconference service.

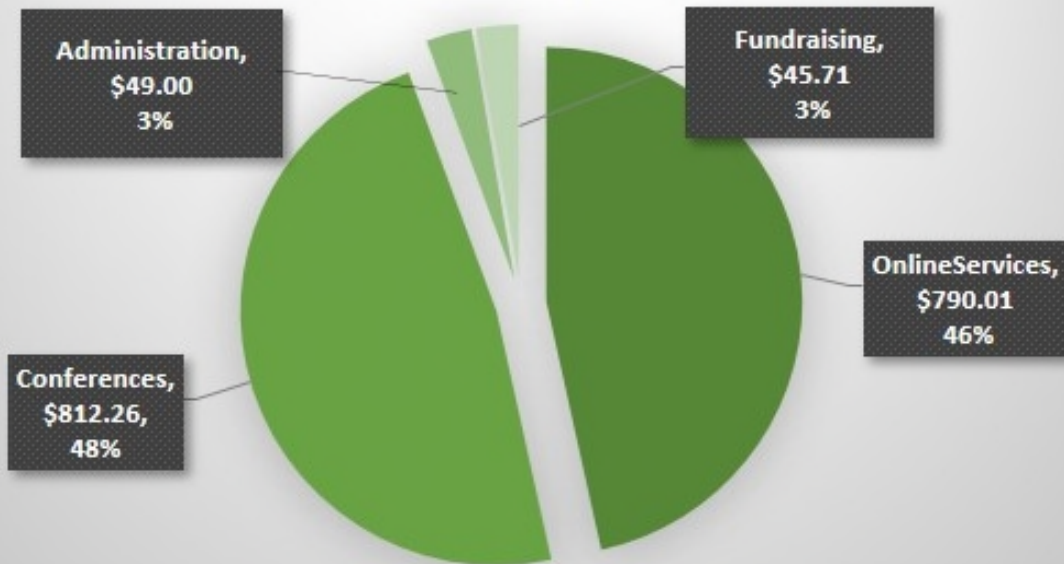
Every Gift Matters!

A BIG thank-you to donors who gave individual contributions and to those who designated **ApoE4.Info Inc** as their [AmazonSmile](https://www.amazon.com/apoe4info) charity.

2019 Contribution by Type

Amazon Smile	\$327.36
Forum	\$7,275.00
Other	\$358.00
Total:	\$7,960.36

2019 Functional Expenses



	Online Services	Conferences	Administration	Fundraising
Business Registration Fees	\$ -	\$ -	\$ 49.00	\$ -
PayPal Fees (donation processing)	\$ -	\$ -	\$ -	\$ 45.71
Telecommunications, hosting	\$ 280.01	\$ 562.26	\$ -	\$ -
Honoraria	\$ 500.00	\$ 250.00	\$ -	\$ -
Advertising Expenses	\$ 10.00	\$ -	\$ -	\$ -

INCOME AND EXPENSE	
Income	
Corporate Contributions	\$327.36
Individual, Business Contributions	\$7,633.00
Interest-Savings, Short-term CD	\$27.23
Total Income	\$7,987.59
Expense	
Business Registration Fees	\$49.00
PayPal Fees (donation processing)	\$45.71
Telecommunications, hosting	\$842.27
Honoraria	\$750.00
Advertising Expenses	\$10.00
Total Expense	\$1,696.98
Net Income	\$6,290.61

