



2018

ANNUAL REPORT



FOUNDATION
of the National Lipid Association

LearnYourLipids.com

PRESIDENT'S MESSAGE

The Foundation of the National Lipid Association made great progress in 2018. Fueled by a reinvigorated mission statement established in 2017, the board and our supporters worked harder than ever to continuously improve the quality of our initiatives and resources, collaborate with like-minded organizations, and recognize the much-needed research of healthcare providers and researchers in our field aiming to close gaps in patient care.

PATIENT INITIATIVES

Find a Lipid Specialist Tool

In an effort to enhance the value of the resources that we provide to patients living with rare lipid disorders and their families and caregivers, we updated our "Find a Lipid Specialist" tool on LearnYourLipids.com this year. Users can now easily locate providers practicing in their area who have been credentialed by the American Board of Clinical Lipidology and the Accreditation Council for Clinical Lipidology.

FDA Open Public Hearing for volanesorsen

On May 9, Foundation board member Lori Alexander, MSHS, RD, CCRC, CLS, FNLA attended a patient stakeholder meeting in Maryland, hosted by Akcea Therapeutics, on behalf of the Foundation. Patients living with Familial Chylomicronemia Syndrome (FCS) and the FCS Foundation leadership were in attendance. The group was presented with qualitative data on the Quality of Life in FCS, Patient Services provided by Akcea and their partners, and learned more about the patient experience directly from patients. Lori presented information on the resources the Foundation provides to patients with rare lipid disorders.

On May 10, in Bethesda, Maryland, Lori testified in front of the Food and Drug Administration Endocrinologic and Metabolic Drugs Advisory Committee during the Open Public Hearing for volanesorsen, a novel therapy for the treatment of FCS. The United States Food and Drug Administration (FDA) issued a Complete Response Letter to the therapy manufacturer on August 27, 2018.

On December 18, 2018, the Foundation and the NLA released an open letter to Familial Chylomicronemia Syndrome patients, supporting their efforts to urge the FDA to approve volanesorsen.

Cholesterol Education Month

On September 18th, the Foundation of the NLA co-hosted a Twitter Chat with MotherToBaby on cholesterol awareness and

management in pregnant women. The Foundation became an official MotherToBaby approved resource and was added to the MotherToBaby website **MotherToBaby.org** in June 2018.

In addition to the Twitter Chat, the Foundation partnered with the NLA during the month of September on a social media campaign featuring highlights from NLA members and Foundation and NLA board members showcasing what they do to stay active and to keep their cholesterol levels in check.

Triglyceride Awareness Campaign

In December of 2017, the Foundation was represented at an advisory meeting at the American Pharmacists Association headquarters in Washington, D.C. to discuss the Foundation's potential involvement in partnering, with 13 other associations/foundations, on a **Triglyceride Awareness Campaign**. In July 2018, the attendees of that meeting held a conference call to discuss the creation of two surveys to gather insights from consumers and healthcare professionals that will inform collective decision making about elevated triglycerides and patient engagement. The two surveys created and conducted in September – November of 2018 intended to identify gaps so that all participating organizations could collectively address the need to close them with the goal of reducing cardiovascular risk and improving the health of those patients we all serve. After the compilation and review of the survey results from all 13 collaborating organizations' respondents, the Foundation met with the group again on November 15, 2018 to develop further consensus about an effective Triglyceride Awareness Campaign. More to come in 2019!

Digital Cookbook for Patients with FCS and FCS Awareness Day- November 2nd

Last year, the Foundation launched a digital cookbook for patients with Familial Chylomicronemia Syndrome as part of our "Rare Disease Awareness Campaign" (RADAR) campaign. In May of 2018, the Foundation of the NLA contacted the original

reviewers of the FCS cookbook to let them know that, in light of the newly released recommendations for FCS patients, “Familial Chylomicronemia Syndrome: Bringing to Life Dietary Recommendations throughout the Life Spam”, the Foundation would work to create new recipe criteria for our cookbook. Mary Felando, Julie Bolick, and Kathy Rhodes spear-headed that initiative and established new recipe criteria. With the tremendous and generous assistance of 9 dietitian volunteers, The Foundation re-reviewed and updated all fifty (50) recipes in the cookbook and relaunched the digital book in time for the first-ever FCS Awareness Day on November 2nd. We hope to add approximately 40 more recipes from caregiver supporter Naomi Hastings to the digital book in 2019 and provide printed copies to patients and caregivers free-of-charge.

Health Screenings

The Foundation of the NLA entered a partnership with Health First Community Health Center in 2018 to provide free LDL-C, TG, and A1C screenings to citizens in rural areas of Kentucky.

We supported the screening of 21 people in Dixon, KY at our first partnered event of the year on September 29, 2018. Foundation board member Joyce Ross, MSN, CRNP, CLS, FNLA attended the screening to provide counselling and interpretation assistance to the participants after they received their test results. 59% of Health First’s patient population have an income level below

100% of the federal poverty level, and 23% have an income level below 200% of the federal poverty level.

On December 21, 2018, the Foundation and Health First Community Health Center supported a local Toys for Tots initiative in Providence, KY. Health screenings were offered to families as they picked up their Christmas gifts. We reached approximately 200 people who may have been without insurance and/or otherwise without access to lipid testing.

The Foundation plans to support several more screenings hosted by Health First to reach more Kentucky residents in 2019.



AWARDS & RESEARCH SPONSORSHIP

The Foundation of the NLA offers several prominent honors and awards each year that recognize individuals and their research in the field of lipidology and rare and genetic disorders. We were humbled to sponsor the recognition of our founding researchers and founders and to honor the following award recipients in 2018:

Donald Hunninghake, MD, Familial Hypercholesterolemia Abstract Award

This award recognizes the best submitted abstract in the area of familial hypercholesterolemia (FH) research. The 2018 recipient was Gina Lundberg, MD, FACC for her abstract, “Finding Familial Hypercholesterolemia in African American Women at a Community Cardiovascular Screening Event”. Dr. Lundberg was selected by a review committee of Foundation Board members. Dr. Lundberg presented her abstract and received her award on Saturday, April 28 during the National Lipid Association’s Scientific Sessions in Las Vegas, NV.

We thank AstraZeneca for their support of this award in 2018.

W. Virgil Brown Distinguished Achievement Award & Lectureship

This award was established to honor the founder of the NLA and an exemplary clinician in the field of lipidology. The Foundation awarded the 2018 award to Penny Kris-Etherton, PhD, RD, CLS, FNLA at the National Lipid Association’s Scientific Sessions in Las Vegas, NV.



We thank the Dyslipidemia Foundation of Boston for its donation in support of the award.

AWARDS & RESEARCH SPONSORSHIP

Clinician/Educator Award



The Foundation annually awards an individual who demonstrates continued excellence in clinical care of patients with lipid disorders and/or excellence in education in the field of clinical lipidology. The 2nd annual Foundation of the NLA Clinician/Educator award was presented to Neil J. Stone, MD, FNLA.

We thank James and Terry Underberg on behalf of the Aaron and Lillie Straus Foundation for their donation in support of the award.

Young Investigator Award

This abstract award annually recognizes five (5) young investigators (in training students, residents, and fellows or members in practice for < 5 years) conducting research in the field of lipidology. The 2018 Young Investigator Award winners are:

First place: Amy McKenzie, PhD for, "Cardiovascular Disease Risk Factor Response to a Type 2 Diabetes Care Model Including Nutritional Ketosis at One Year"

Second place: Seth Martin, MD, MHS, FACC for, "Martin/Hopkins Estimation, Friedewald and Beta-Quantification of LDL-C in Patients in FOURIER"

Third place: Qian Ye, MD for, "Effect of PCSK9 Inhibitors on Plasma Ceramide Levels"

Fourth place: Anish Vani, MD for, "Elevated Lipoprotein (a) Masquerading as Homozygous Familial Hypercholesterolemia"

Fifth place: Anum Saeed, MD for, "Do Biomarkers Improve Short-term Risk Prediction of Global Cardiovascular Events in Older Adults"

We thank Sanofi-Regeneron for their support of this award in 2018.

Akira Endo Award

This award was created in honor of Dr. Akira Endo, the scientist responsible for the discovery of the statins, the drug class that has had the greatest demonstrable impact on arteriosclerosis of any pharmacological therapy in the history of medicine. This triennial award intends to recognize those responsible for the development of new therapies documented to prevent cardiovascular disease and atherosclerosis. The Foundation and the National Lipid Association, represented by Drs. W. Virgil Brown and Alan S. Brown, presented the 2018 Akira Endo Award at the International Atherosclerosis Society's International Symposium on Atherosclerosis in Toronto on June 9 to our award winners, Dr. Jonathan Cohen of Dallas and Dr. Nabil Seidah of Montreal. We thank Denka-Seiken Corporation, the Dyslipidemia Foundation of Boston, and the Joel Spira Foundation for their support.



Memorial Wall

The Memorial Wall is presented at the National Lipid Association (NLA) Scientific Sessions each year to posthumously honor the leaders and pioneers who were instrumental in shaping the field of clinical lipidology. The Scientific Sessions was selected as the home for this Memorial in order to allow those healthcare providers, researchers, and academics who were and continue to be greatly impacted by the work and influence of the honorees to visit and pay their respects.

In addition to the live presentation at the NLA Scientific Sessions, the Memorial Wall is posted on the NLA's website, www.lipid.org, for members and nonmembers of the organization to view year-round.

Honorees added to the wall in 2018 include Howard A. Eder, MD (1917-2004) and Gerald M. Reaven, MD (1928-2018).

FOUNDATION FUNDRAISER

Foundation of the NLA 2018 Gala and Silent Auction

Our 2018 Dinner Gala & Silent Auction at the Scientific Sessions in Las Vegas was a smashing success, raising \$22,098 in ticket sales and auction bids, with a total of \$72,098 including industry sponsorships, in support of the Foundation of the National Lipid Association's important patient awareness initiatives.

Attendees participated in a silent auction that featured donated sports memorabilia, jewelry, fine wines, vacation getaways and more. Entertainment was provided by NLA President Alan S. Brown, MD, FNLA and his band, This End Up.

I would like to thank everyone who has supported the Foundation of the National Lipid Association in 2018- by volunteering to work on our patient resource initiatives or awareness campaigns, attending a fundraiser, purchasing a Lipids Are My Life shirt at an NLA conference, speaking with your colleagues and patients about the Foundation, or making a donation.

The Foundation remains focused on its mission to improve the welfare of patients and families affected by cholesterol and triglyceride problems. With your help, we are able to expand our offerings and services to reach more patients, families, and caregivers. I look forward to seeing each of you in 2019.

For more information on the Foundation, its initiatives, and resources, visit learnyourlipids.com.

Anne C. Goldberg, MD, FNLA
President

Foundation of the National Lipid Association

These pioneers will continue to be remembered for their outstanding contributions to lipidology. To visit the memorial wall online, visit lipid.org/memorialwall.

International Museum of Surgical Science – Understanding Lipoproteins: Research, Treatment and Relationship to Cholesterol

The Foundation sponsored the International Museum of Surgical Science's exhibit honoring the discoveries made by University of Chicago physician Dr. Angelo M. Scanu, Understanding Lipoproteins: Research, Treatment and Relationship to Cholesterol, which opened on November 10, 2018 during the Lp(a) Foundation's Hope Gala. The exhibit can be viewed at the museum through November 2019. The Foundation of the NLA remains dedicated to honoring research that moves the needle in patient care and fosters awareness of the effects of lipoproteins.



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OUR MISSION

The Foundation of the National Lipid Association is a patient-focused nonprofit organization dedicated to improving the welfare of patients and families affected by cholesterol and triglyceride problems.

DONATIONS

The Foundation recognizes two individual donor contribution levels: Sustaining and Contributing. Sustaining Donors make a gift of \$1,000 or more throughout the course of the year. All other private donations are considered Contributing Donors. Donations of all sizes are greatly appreciated and help make Foundation initiatives possible.

Thank you to our Sustaining Donors in 2018:

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James and Terry Underberg *on behalf of the Aaron and Lillie Straus Foundation*
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Thank you to our Contributing Donors in 2018:

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FUNDRAISING

Thank you to our In-Kind Donors in 2018:

Edward R. Chafizadeh, MD
Linda C. Hemphill, MD, FNLA

James A. Underberg, MD, MS, FNLA
Terry Underberg

Scan for Lipids

2018 was the 8th year the Foundation benefited from the National Lipid Association's "Scan for Lipids" program at its scientific meetings. Participating exhibitors who purchased a lead retrieval scanner donated a portion of their purchase to the Foundation.

Thank you to our "Scan for Lipids" Donors in 2018:

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Industry Support

The Foundation of the NLA seeks support from partners in relevant industries for projects that encourage research in the field and benefit education of healthcare providers that enables enhanced patient care.

Thank you to our Industry Supporters in 2018:

American Pharmacists Association

Amgen

Denka Seiken Company, Ltd.

Dyslipidemia Foundation of Boston

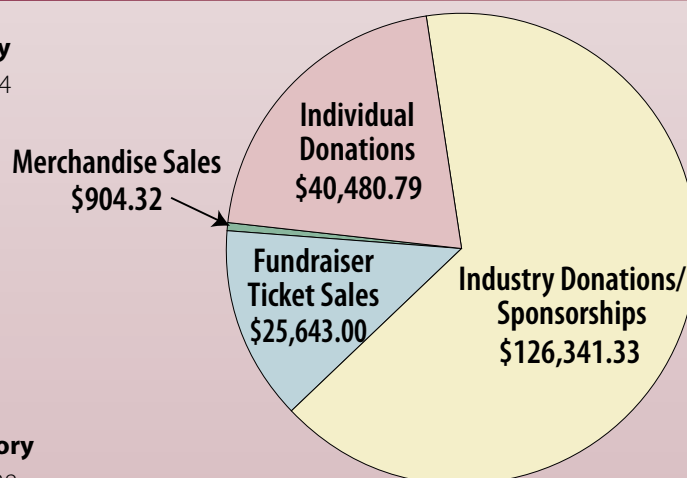
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2018 FINANCIAL REPORT

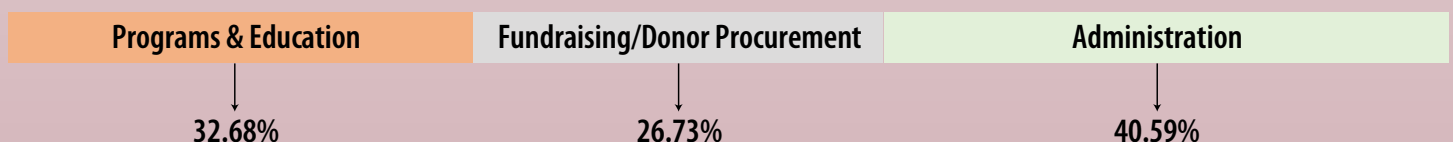
2018 Income by Category

Total Revenue – \$193,369.44



2018 Expenses by Category

Total Expenses – \$209,709.38



The Foundation of the NLA is a registered 501(c)(3) organization | EIN: 20-1576306