



ANNUAL REPORT 2020

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A LETTER FROM THE PRESIDENT

Global DARE Foundation has had an amazing first year. We hit the ground running with our launch in October 2019. We set a clear mission to improve the lives of those who have been diagnosed with Adult Refsum Disease. I have had the pleasure over the last year to meet so many wonderful people within the Refsum Community.

Global DARE Foundation established a set of measurable goals for 2020 focused on improving treatment and care, advancing research, raising awareness and collaborating. As you will see in our accomplishments, we have achieved everything we set out to do in our first year.



Shortly after starting Global DARE Foundation, we made some strategic partnerships with umbrella organizations to help us advance faster. United Leukodystrophy Foundation (ULF), NORD, Global Genes, Findacure, and Foundation Fighting Blindness to name a few. These partnerships made all the difference in our ability to mature quickly and accomplish our goals.

With the encouragement of Bob Rauner, President of ULF, I joined their board of directors. Joining the ULF board allowed me to learn everything I needed to know about jumpstarting a foundation in a short period of time. I met Dr. Joe Hacia, PhD at the ULF board meeting (picture on the left). Joe

has become an amazing advocate for Refsum research and became the co-chair of our Medical and Scientific Advisory Board.

We are fortunate to have an advisory board made up of the foremost researchers and clinicians in the field of Refsum Disease, peroxisomal disorders and Retinitis Pigmentosa. The team is driving forward better treatment and care, research and collaboration.

In February of 2020, Global DARE Foundation participated in Rare Disease week at Capitol Hill. During that visit, I had the pleasure of meeting with the wonderful team (Ann Moser, Hong Breerton and Dr. Paul Watkins, MD, PhD) at Kennedy Krieger Institute (picture on the right). All 3 of them have been actively engaged with us in our research initiatives.



I am so thankful to all of our supporters that helped us throughout the year by volunteering and donating. None of this would have been possible without all of you. We are positioned well for continued success in 2021!

Kristie DeMarco | President
Global DARE Foundation

BOARD OF DIRECTORS

Our Board of Directors are part of the Refsum Disease Community and are highly motivated to do whatever it takes to find better therapeutic methods and ultimately a cure. We are fighting with the disease on a day-to-day basis. This gives every aspect of what we do more purpose and meaning as it directly affects as well as inspires us!



**Kristie DeMarco,
President**



**Susan Kuranoff,
Secretary**



**John DeMarco,
Treasurer**



**Alan Gunzburg,
Director**



**Kim Bruce,
Director**

MEDICAL & SCIENTIFIC ADVISORY BOARD

We are fortunate to have an advisory board made up of the foremost researchers and clinicians in the field of Refsum Disease, peroxisomal disorders and Retinitis Pigmentosa. In their roles as medical and scientific advisers, members collaborate with each other and with our Board of Directors to drive forward better quality of life for those diagnosed with Refsum Disease.



Florian Eichler, MD
MSAB Chair



Ronald Wanders, PhD
MSAB Co-chair



Joe Hacia, PhD
MSAB Co-Chair



Radha Ramachandran, MD, PhD



Anthony Wierzbicki, PhD



Eleanor Baldwin,
Dietician



Nancy Braverman, MD,
MS



Mousumi Bose, PhD



Sacha Ferdinandusse,
PhD



Bart Leroy, MD, PhD



Arthur Bergen, PhD



Clara van Karnebeek,
PhD



Hans Waterham, PhD



Sarah Firman, Dietician



Paul Watkins, MD, PhD

YEAR 1 ACCOMPLISHMENTS

Launch of Global DARE Foundation



We launched Global Dare Foundation in October 2019 and set a clear mission along with measurable goals for 2020. Our mission is to promote worldwide awareness and a better quality of life for all who are diagnosed with Adult Refsum Disease. Our 2020 goals centered around research & care, raising awareness and collaboration.

Website & 1st Fundraiser Launched

We launched our website and first fundraiser in November 2019. We had a limited budget, so we built our website using WIX. By using a website platform not requiring a web developer we were able to be very dynamic with our website and have matured it over the year. Our first fundraiser was a success raising just over \$10,000.



Medical & Scientific Advisory Board



We established our Medical and Scientific Advisory Board early, which has made a tremendous difference in our success. It provided us credibility with everyone we reached out to in raising awareness for Refsum. This board is driving treatment and care, research, and collaboration amongst experts in the field.

YEAR 1 ACCOMPLISHMENTS CONTINUED

Announced First Research Project



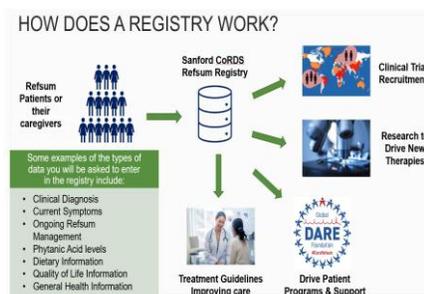
By March of 2020, we had our second fundraiser and as a result announced our first research project which involved testing food for its phytanic acid content. People with Refsum are on an extremely strict diet. Testing more foods will ensure people are eating safe foods. This will be a quick win for our community.

Launched Webinar Series

Our London conference was canceled due to COVID so we launched a webinar series. The webinar series covered topics on the clinical and scientific background of Refsum, the specialized Refsum Diet and Gene Therapy as a potential future therapy for Refsum. It was a great success and substantially broadened our Refsum Community.



Rolled out a Refsum Patient Registry



We rolled out the first ever patient registry on Refsum disease. This patient registry is sponsored by Sanford CoRDS. This will be a great resource for us to better understand the disease, help us understand where to drive our research initiatives and provide guidance on areas where patients need more support.

YEAR 1 ACCOMPLISHMENTS CONTINUED

Country Ambassador Program



We launched a Country Ambassador program as part of our campaign to raising awareness of Refsum around the world. Our goal for the program is to get people diagnosed earlier and connect with more people who have already been diagnosed. Currently, we have ambassadors established in 6 different countries.

Refsum Mouse Model

In October 2020, our research team started the plan to bring the Refsum Mouse model to Johns Hopkins. This will be the first step to reinvigorate the research around Refsum. Once the mouse model is established, we will look to move forward with a pilot study in gene therapy.



Raised \$49,000 in the first 14 months



Even with a disease that is 1 in a million, it is possible to raise funding. We wrapped up the year with the DARE Step Challenge that raised \$15,000 toward our pilot study in gene therapy. Overall, for the first year, we ran 3 successful fundraisers which raised \$49,000.

FINANCIAL UPDATE

Thanks to our generous donors, Global DARE Foundation raised \$49,000 in our first 14 months which has positioned us well to start valuable work into improving the lives of people diagnosed with Refsum Disease. Our organization is led by a 5-member board of directors. We have no paid staff, but we do have essential annual expenses such as maintaining our website. Our leadership is focused on maintaining low overhead so that we can maximize our investment in research, education, and awareness.

2019 & 2020 - Income

\$10K

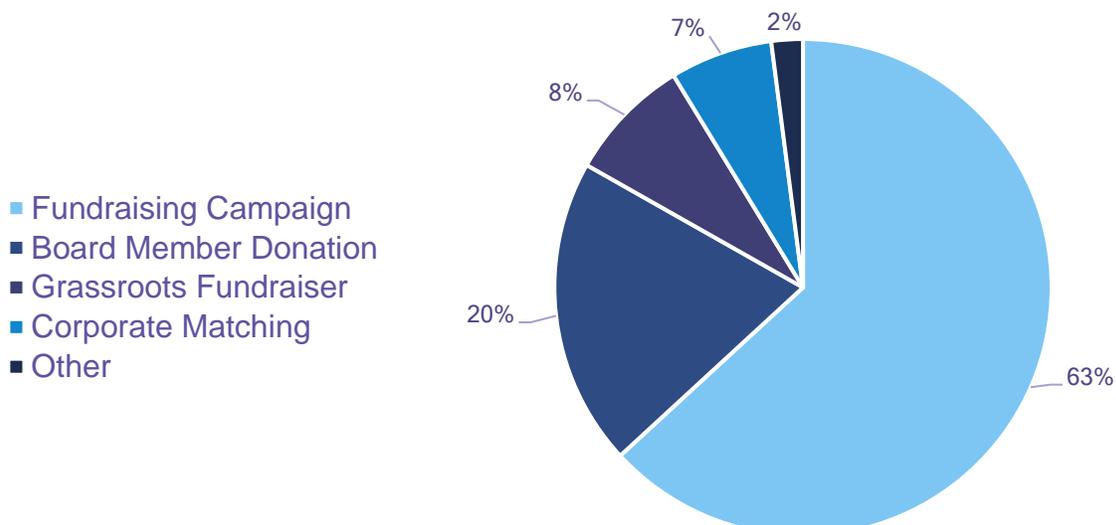
2019

\$39K

2020

*2019 started in October and 2020 is through November 30th.
\$3K in additional income expected.

Fundraising Efforts



FINANCIAL UPDATE CONTINUED

2019 & 2020 – Expenses

\$3.5K

2019

\$3.2K

2020

*2019 started in October and 2020 is through November 30th.
\$2k additional expense is expected in support our Raising Awareness Campaign

Expense Breakdown % of Income

Expense	2019	2020
Operating	24.3%	2.9%
Fundraising	9.5%	2.8%
Programs	0%	2.5%
Total	33.8%	8.2%

Notes of interest:

- 2019 was our startup year which included \$1,815 in legal fees to establish the 501(c)(3).
- In 2020 we have found ways to reduce our payment processing fees by using platforms that either charge no fees, reduced fees or fees that can be paid by the donor.
- We anticipated \$5,000 in conference fees but with the move to a webinar series, we reduced program expenses.
- Our phytanic acid food project has seen delays due to COVID so the \$12,000 expense expected in 2020 will move to 2021.