

THE MOG PROJECT

2021 ANNUAL REPORT



A Year of Forming a MOG Nation



WHO WE ARE

We are a group of patients and caregivers whose lives and the lives of our loved ones have been affected by Myelin Oligodendrocyte Glycoprotein Antibody Disease (MOGAD or MOG for short). At the end of 2017 after our Executive Director experienced terrible, life altering medical effects brought on by this disease and unable to find information, we formed this organization to support those diagnosed no matter what age or nationality. While originally operating under the umbrella of the Siegel Rare Neuroimmune Association (SRNA) we decided to formalize an organization solely dedicated to MOGAD. In January of 2021, we officially received our 501(c)(3) US non-profit status and were ready to hit the ground running. And amazingly we did.

WE ARE...

5 EXECUTIVE
BOARD
MEMBERS

5 ADVISORY
BOARD
MEMBERS

17 MEDICAL
ADVISORY
BOARD
MEMBERS

6 MOG
PROJECT
CHAMPIONS
& INTERNS

We are **The MOG Project** and we are on a mission!

The MOG Project is devoted to raising awareness, educating doctors, patients and caregivers, advancing research through expert collaboration and fundraising, and providing support and advocacy for our community in hopes of finding a cure.



A NOTE FROM THE PRESIDENT & EXECUTIVE DIRECTOR

With the approval of our 501(c)(3) status in January of 2021, the possibilities to help the MOGAD community grew immensely. All our hard work to set up the organization had finally paid off. We spent 2020 going through the lengthy approval process for our 501(c)(3) status but this did not stop our fabulous team from moving forward in helping patients. We accomplished so much in that year of 2020. In 2021, as an official non-profit organization, the team kept up the MOGmentum and continued working with our partners and medical professionals to provide patients with the best and most accurate information on MOGAD. We spent the year building a team of MOGAD experts to populate our Medical Advisory Board, who are behind all our resources for patients. We started our own podcast program, called The MOGCast Series with development under the leadership of Peter Fontanez, our Director of Resources and Advocacy. We continued our patient survey efforts with a new Ignition Survey on fatigue in MOGAD, a program inspired by the idea of our Patient Advocacy Specialist, Chuck Bies and made a reality by Jen Gould, Director of Patient Insights. We expanded our resources with another MOGmentum Series in collaboration with the Sumaira Foundation and more blind resource offerings led by our Director of Blind Resources, Andrea Mitchell.

We were thrilled to auction our second barrel of Blanton's Bourbon thanks to Buffalo Trace Distilleries in Frankfort, Kentucky for a whopping \$51,600! This all was captured by our sponsors, Kimball Hughes Public Relations and we were able to bring awareness to MOGAD through them in collaboration with our Chief Media Officer, Jim Broutman.

Some new developments came to The MOG Project in the form of a new Advisory Board Member, Jenny Khazen from Australia who acts as our Australian Ambassador and has been an important part of our medical professional outreach. We started 3 age related support groups with the help of Becca Salky and Dawn and Brian Groves.

Pharma companies started to notice our work and recognize our expertise and insight into patient experience. This led to the year ending with forming new relationships with these companies.

2021 was an amazing year! Stay tuned for next year – we expect good things to report!

-Amy Ednie, President

-Julia Lefelar, Executive Director



OUR EXPANDING TEAM

In 2021, our Medical Advisory Board expanded with the addition of:

- Dr. Jon Santoro, a pediatric neurologist from University of Southern California in LA (he was mentored by Dr. Tanuja Chitnis).
- Dr. Jackie Palace from Oxford. She is an expert in MOG-AD research both in the UK and worldwide.
- Drs. Sudarshini (Darshi) Ramanathan and Russell Dale as well as A/Prof Fabienne Brilot (the *Dream Team* in Australian research) from the University of Sydney and the Kids Neuroscience Centre.
- Dr. Elia Sechi, a neurology consultant at the Department of Medical, Surgical and Experimental Sciences at the University of Sassari (Italy), where he completed medical school and neurology residency.

We have also added an additional member to our Advisory Board, Jenny Khazen from Sydney, Australia, who is our Australian Ambassador and Medical Professional Outreach Specialist. Jenny has helped us expand our social media network to Twitter, which started with 20 followers and now has over 790 followers, connecting us with national and international doctors, clinicians, scientists, and researchers and helping us access the latest information, podcasts and webinars for MOGAD. She helped us expand our medical network internationally, bringing to the Medical Advisory Board Dr. Sudarshini Ramanathan, Associate Professor Fabienne Brilot and Professor Russell Dale from Sydney, Australia as well as Dr. Elia Sechi from Italy. Jenny raised over \$2000 in May 2021 in a combined fundraiser for The MOG Project and the Kids Neuroscience Centre to raise awareness for MOGAD from a Primary Teacher's perspective and as a MOGAD patient. She wrote a MOG Blog titled *Entering the World of MOGAD* about her journey towards a MOGAD diagnosis and also collaborated with Julia Lefelar on the formation of a follow-up MOG Blog titled *MOGAD Diagnosis: Testing and Titors* with Dr. John Chen and Dr. Eoin Flanagan from the Mayo clinic. Jenny has also helped develop our second Ignition Survey on Fatigue in MOGAD and took on the role of organizing, analyzing, and presenting the data. We welcome Jenny to The MOG Project as an official MOG Squad member!



NEW PARTNERSHIPS

Part of our mission has been to collaborate with like-organizations who share the same values and align with our mission to help patients everywhere. Joining our existing partners (Siegel Rare Neuroimmune Association and The Sumaira Foundation), we were excited and proud to become collaborative partners with two new organizations who have built a community of followers in rare neuroimmune conditions:

- MyMyelitis (<https://mymyelitis.com/>)
 - Run by Scott Tarpey from the United Kingdom to help patients there understand their MOGAD diagnosis.
- Guthy Jackson Charitable Foundation (<https://guthyjacksonfoundation.org/>)
 - Started by the Victoria Jackson for her daughter Alli Guthy, a sufferer of NMOSD.

We are excited to collaborate with these organizations and look forward to a long and fruitful relationship to benefit our rare neuroimmune communities!



NEW RESOURCES

Patient education is of the highest priority, so we added several resources:

- MOGmentem #4: This 4th installment in the series took a DEEP DIVE into MOGAD symptoms with the help of Dr. Elias Sotirchos from Johns Hopkins Medicine.
- We expanded Blind Resources and created the first of two Blind Insight Videos created by our own Director of Blind Resources, Andrea Mitchell. These videos demonstrate some useful tools for those who are blind or visually impaired:
 - Script Talk: <https://youtu.be/Nobbi4n1YAO>
 - QR Code Digital Access Menus: <https://youtu.be/RGbX1QvJ6AU>
- Update to the Fact Sheet for Educators: Thanks to Dawn Groves, Peter Fontanez and Jen Gould as well as Dr. Brenda Banwell for her insight and expertise, we made important updates to this useful resource we created in collaboration with our partners at the Siegel Rare Neuroimmune Association (SRNA).
- Kickoff of our second Ignition Survey on Fatigue in MOGAD with the help of Dr. Elias Sotirchos and Dr. Bardia Nourbakhsh of Johns Hopkins Medicine.
- New Podcasts
 - MOG-AD Diagnosis, Testing and Titers with Dr. John Chen and Dr. Eoin Flanagan: https://youtu.be/8-MDEOd_08Q
 - The Latest from The MOG Initiative with Dr. Michael Levy: <https://youtu.be/OafxpUB6eas>



NEW SUPPORT GROUPS

We now offer zoom-based support groups to our MOGAD Community! We dedicated a page on our website to helping patient sign up to share experiences, ask questions, and collaborate on the best ways to self-advocate and talk to your doctor:

- *The Lil' Hummingbird Nest* is run by Dawn and Brian Groves and is for parents and caregivers of children with MOGAD.
- *Lifting the MOG Fog*, run by Becca Salky, is geared for adults 18-30.
- *MOG Slogger: Finding Our Way Together* is a support group run by our own Executive Director, Julia Lefelar and Director of Blind Resources, Andrea Mitchell.
- *Nattering our Way Through the Unknown*, run by Laura Hinde, invited all adults to join. This group was geared toward MOGAD patients in the UK.

COMMUNITY OUTREACH

Our community is important to us, and we have had the opportunity to connect with some of our patient community members this year:

- Spotlight on Maya DiMauro and her patented invention, The SurvIVe Pillow for users of IVIG. Maya was featured on Connecticut Invention Convention social media as an *Inventor of the Week* in April of 2021
- The 12 Days of Christmas Video
(<https://www.youtube.com/watch?v=2Jm0D-s0PHc>)



CONTRIBUTIONS TO RESEARCH

We partnered with the Neuroimmunology Clinic and Research Laboratory as part of Dr Michael Levy's MOG Initiative at Massachusetts General Hospital. The MOG Initiative targets specific research related to MOGAD and there were several areas where we participated to make an impact:

- Helped to recruit patients for a survey on nutrition by Dr. Michael Levy.
- Assisted in the creation of a fundraising video from community submissions: <https://youtu.be/OY7qIWX1c4A>
- Helped request blood samples from MOG patients for two upcoming studies:
 - Searching for genetic markers of MOGAD
 - Determining what parts of the immune system are reactive in MOGAD so that we can best target medications.
- Helped recruit patients for a study on IVIG. They wanted to study the safety and effectiveness of IVIG alone or in conjunction with IV steroids for relapses in MOGAD patients.
- Partnered with Dr. Michael Levy and The MOG Initiative to recruit patients that would participate in a study to understand whether eye color has any effect on light sensitivity after optic neuritis in MOGAD patients.
- Helped to recruit NMO patients with AQP4, MOG or seronegative disease for a short survey on pain and quality of life.

We also connected with pharma and had the opportunity to contribute to their research as well:

- Connecting patients with the MOGAD Patient Journey Project sponsored by Just World Wide (<https://www.just-worldwide.com/>). This research project interviewed patients about their experience with the disease, providing valuable data to Pharma.
- We partnered with Savvy Cooperative (<https://www.savvy.coop/>) which helps to gather patient insight for companies who are researching diseases, including NMOSD. We helped them recruit patients for projects in need of patient experience which provided valuable insight to researchers developing treatments for MOGAD
- Partnered with the Healthcare Innovation Company, Worrell (www.worrell.com) to allow adolescents with MOGAD to weigh in on the medicine delivery system design for medicines being developed for MOGAD.



CONFERENCE PARTICIPATION

We were invited to attend the Siegel Rare Neuroimmune Association Rare Neuroimmune Disease Symposium on October 8-10, 2021. This was a great opportunity to reach the growing MOGAD community. Due to COVID, we set up a virtual booth and provided patients with educational materials and support. We truly appreciate the SRNA for their invitation to join them!

CORPORATE & PRIVATE SPONSORS

- **Kimball Hughes Public Relations:** Kimball Hughes is a Philadelphia based national public relations agency rooted in the fundamentals of good journalism and persuasive storytelling. Thanks to the efforts of Eileen Coyne, James McKinsey and Kate Glaviano, we were able to get several stories published on a national level and were featured in a television broadcast as well as two radio broadcasts.
- **Gina Hessburg:** Rafael and her book *Blowing Up: a coffee table book about her life with a friend made of plastic who served as her companion while she lived a solitary life social distancing during the COVID-19 pandemic.* Gina donated a portion of the sales of her book to reputable researchers and The MOG Project, spreading awareness for Optic Neuritis in a very clever way.

FUNDRAISING

With so many diagnosed with rare diseases and not knowing where to turn, funding for organizations like ours is critical to the support and education of those living with and affected by MOGAD, as well as to the continued search for a cure. We raised more than \$51,000 during our Blanton's bourbon auction sponsored by Buffalo Trace Distilleries in Frankfort, Kentucky. On a platform provided in-kind by Unicorn Auctions, we hosted a charity auction for a rare barrel of Blanton's bourbon and VIP experience at the Frankfort, Kentucky-based Buffalo Trace Distillery. The auction winners, a group of bourbon lovers who wish to remain anonymous, received the opportunity to sample from a variety of Blanton's finest bourbon barrels, and choose their own 53-gallon barrel, constituting approximately 217 bottles. We are grateful to all who participated in this auction and particularly to our generous winners.



PRESS

Thanks to the sponsorship of Kimball Hughes Public Relations, we had some great exposure, and we were able to get MOGAD in the press:

- Washington DC NBC4 interview on the Whiskey Sale (aired 3 separate times)
 - <https://youtu.be/1aFt4O64qD0>
 - <https://youtu.be/Kik005jW1M0>
- The MOG Project Formally Launches as 501(c)3 to Raise Profile of Often Misidentified Neuroinflammatory Disease, MOG-AD
 - https://www.prweb.com/releases/the_mog_project_formally_launches_as_501c3_to_raise_profile_of_often_misidentified_neuroinflammatory_disease_mog_ad/prweb18018864.htm
- Charity Auction Aims to Put MOG Antibody Disease Over a Barrel
 - https://www.prweb.com/releases/charity_auction_aims_to_put_mog_antibody_disease_over_a_barrel/prweb18345872.htm



KEY DATES

- 1/21/21: Officially announced our IRS 501(c)(3) status
- 1/30/21: Expanded our social media reach by joining Twitter
- 5/26/21: Established Collaborative Partnership with MyMyelitis
- 6/19/21: Announced Fundraising opportunities through Facebook, Instagram and Amazon Smile
- 9/1/21-9/30/21: Blanton's Whiskey Barrel and Experience Auction
- 10/8/21-10/10/21: The MOG Project holds a booth at the Siegel Rare Neuroimmune Associate Rare Neuroimmune Disease Symposium Virtual Event.

STATISTICS AND INSIGHTS

Social Media Stats as of June 25, 2022

11 Countries

- Facebook
 - Page Reach: 24,785
 - Page Visits: 2882
 - Followers: 1531
- Instagram
 - Page Reach: 937
 - Page Visits: 1547
 - Followers: 512
- Twitter 881 followers

Wings of Hope Support Group Stats:

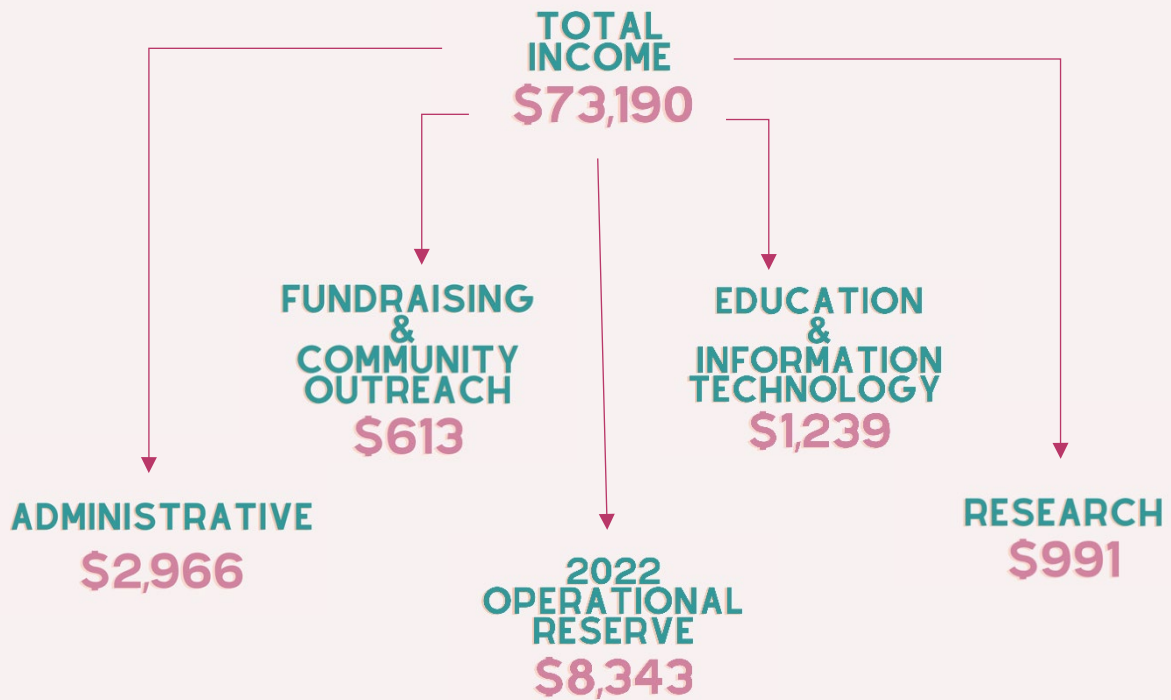
- Lil' Hummingbird Nest: 8 meetings
 - Dr. Brenda Banwell visited in September
- MOG Sloggers: Finding our Way Together: 8 meetings
- Lifting the MOG Fog: 20 meetings
 - Dr. Michael Levy visited in September
- Nattering Through the Unknown: 3 meetings



BUDGET

We are extremely grateful for each donation dollar and so we recognize the importance of our jobs as stewards of these gifts designated to serve the MOGAD patient community. For this reason, we remain as frugal as possible to get the job done, relying on a 100% volunteer staff, and our MOG Squad of volunteers.

What we spent in 2021



Earmarked for 2022

Research Grant Funding ~\$50,000
Media and Education ~\$9,000



THANK YOU!

For your support of The MOG Project and our MOGAD Community

With your support, we have been able to rapidly fill the needs of MOGAD patients worldwide. We will continue to fill gaps in patient needs and push for research and development of more effective treatments. Rare disease research is difficult but with a growing number of voices we will be able to reach our goal of finding a path to a cure.

Our Board of Directors:

- ❖ *Amy Ednie, President & Co-Founder*
- ❖ *Julia Lefelar, Executive Director & Co-Founder*
- ❖ *Peter Fontenez, Treasure & Director of MOG-AD Resources and Advocacy*
- ❖ *Jen Gould, Recording Secretary & Director of Patient Insights*
- ❖ *Andrea Mitchell, Director at Large & Director of Blind Resources*

Our Medical and Scientific Advisory Board

- ❖ *Michael Levy MD, PhD, Massachusetts General Hospital, Harvard University*
- ❖ *Elias Sotirchos, MD, Johns Hopkins Hospital, Johns Hopkins University*
- ❖ *May Han, MD, Stanford Hospital, Stanford University*
- ❖ *Tunuja Chitnis, MD, FAAN, Brigham and Women's Hospital, Harvard University*
- ❖ *Linda Tardo, MD, UT Southwestern Medical Center*
- ❖ *Brenda Banwell, MD, FRCPC, FAAN, Children's Hospital of Philadelphia*
- ❖ *Sean Pittock, MD, MAYO Clinic*
- ❖ *John Chen, MD, PhD, MAYO Clinic*
- ❖ *Eoin P. Flanagan, M.B., B.Ch., MAYO Clinic*
- ❖ *Jonathan Santoro, MD, Children's Hospital Los Angeles, University of Southern California*
- ❖ *Jackie Palace, BM, FRCP, DM, Oxford University*
- ❖ *Sudarshini Ramanathan, MD, PhD, Kid's Neuroscience Centre, University of Sydney*
- ❖ *Fabienne Brilot, PhD, Kid's Neuroscience Centre, University of Sydney*
- ❖ *Russel, Dale, MD, PhD, Kid's Neuroscience Centre, University of Sydney*
- ❖ *Elia Sechi, MD, University of Sassari*
- ❖ *Lisa K. Ryan, PhD, University of Louisville*
- ❖ *Gill Diamond, PhD, University of Louisville*



Our Advisors, Champions, and Interns

- ❖ *Kristina Lefelar, Digital Marketing and Media Consultant & Co-Founder*
- ❖ *Jim Broutman, Chief Media Officer*
- ❖ *Diana Lash, Patient Advocacy Specialist*
- ❖ *Chuck Bies, Patient Advocacy Specialist*
- ❖ *Jenny Khazen, Australian Ambassador & Medical Professional Outreach Specialist*
- ❖ *Pamela Fontanez, MOG-AD Advocate*
- ❖ *Lisa Kovanda, MOG-AD Advocate*
- ❖ *Dawn & Brian Groves, Support Group Leaders - Lil' Hummingbird Nest*
- ❖ *Becca Salky, Education Consultant and Advocacy Specialist & Support Group Leader – Lifting the Fog*
- ❖ *Chelsea Ednie – Student Intern*

