



MOYAMOYA FOUNDATION

Moyamoya Foundation Co is a qualified 501(c)3) charitable non-profit foundation.

**Welcome to the first Moyamoya Foundation Newsletter!
Get to know the Moyamoya Foundation and what we're working on!**

Who are we?

The Moyamoya Foundation was started with the goals of helping those battling Moyamoya find assistance and support, promoting awareness, and aiding in research to better understand and fight Moyamoya. The Moyamoya Foundation was founded by Victoria Warren after her cousin Samantha Houle was diagnosed with Moyamoya and she noticed the lack of a Moyamoya specific organization to donate to. Samantha was able to quickly obtain a surgery slot due to another patient's lapse in insurance and while fortunate for Samantha it showed a need for assistance in the Moyamoya community.

Newsletter Feature: Meet The Board

We will introduce you to a different Board Member in each Newsletter!

[Dean Houle, President & CEO](#) - Dean was first introduced to the rare disease community when his daughter Samantha (The inspiration for the foundation.) was diagnosed with Moyamoya Disease and his niece, Victoria, had the idea for the foundation. Dean has volunteered in his community for over twenty years and hopes to continue to give back to the Moyamoya community.



Moyamoya Disease Seminar for Patients & Families



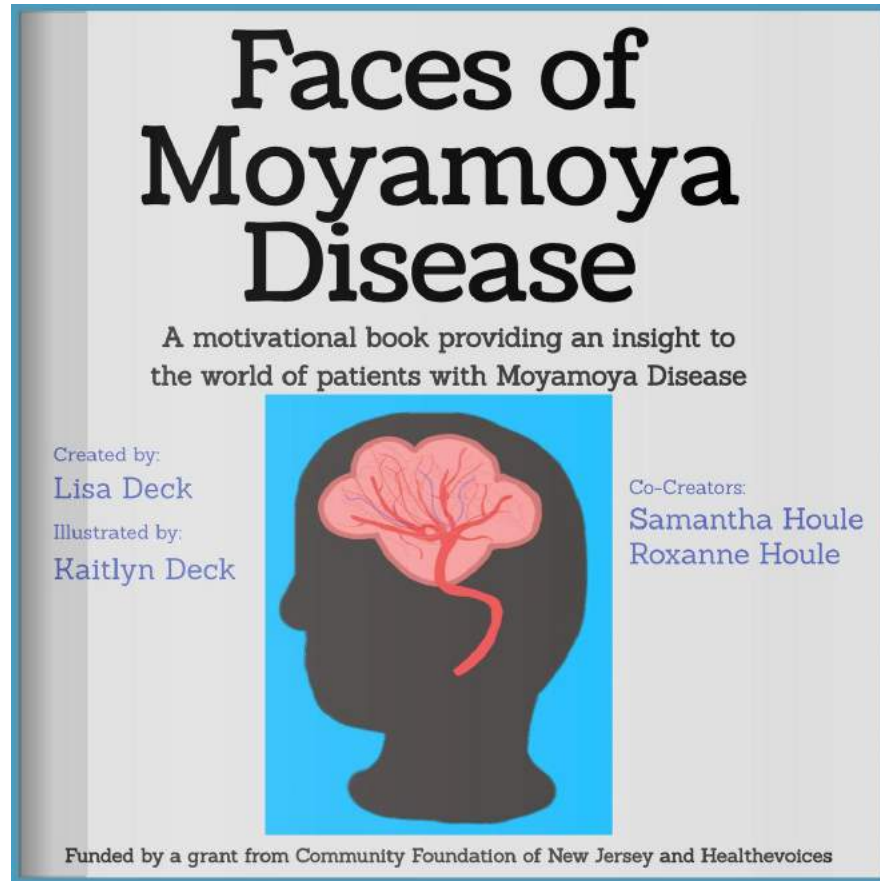
The Moyamoya Foundation co-sponsored the Moyamoya Disease Seminar for Patients and Families on World Moyamoya Day, May 6th, 2021 in Boston, MA. Hosted by the Beth Israel Deaconess Medical Moyamoya Center at the Fairmont-Copley Hotel, this event included information, patient stories, support and networking with doctors from Beth Israel Deaconess Medical Center, Boston Children's Hospital, Boston Medical Center and patients Corey Repucci, Samantha Houle and Lisa Bayha Deck. Over 55 people attended this in-person event, while the online event brought in over 150 live viewers. On YouTube, the event has received hundreds of views and is still available if you missed it live.

[▶ BIDMC 05 06 21 Seminar for Patients & Providers](#)

The event was very successful and was a great chance to bring together the Moyamoya community, especially in the current times. Co-sponsoring the event with Boston Children's Hospital, the Credit Union for Kids and the Repucci family was a special opportunity for the Foundation.

The Moyamoya Foundation had printed copies of the recently published Faces of Moyamoya Disease book, which was created by Lisa Deck, Roxanne Houle & Samantha Houle. A number of the featured patients enjoyed signing copies of the book for conference participants that received copies. A great collaboration and connection opportunity!

Upcoming Sequel to Faces of Moyamoya book



The first *Faces of Moyamoya Disease* book was created by Lisa Deck with a grant received through the Community Foundation of New Jersey and Healthvoices. The book is a resource for Moyamoya patients and their families which shares the personal stories from many Moyamoya patients. The first book included stories from 37 patients and we hope to include many more in the coming *Faces of Moyamoya Disease* book. This second book is going to be supported by the Moyamoya Foundation directly and we hope it can continue to bring the Moyamoya community together. Interested in being featured in our second book? Please reach out to mymoyamoyastory@gmail.com to learn more!

Global Moyamoya Disease Patient Registry

The Moyamoya Foundation is excited to announce that we are creating a global patient registry which will be used to further research about moyamoya. The registry will be housed in a health data platform that was formed through a partnership between Genetic Alliance's Platform for Engaging Everyone Responsibly (PEER) and LunaPBC™.

What is a patient registry?

A patient registry is an organized data system that collects information from patients diagnosed with a particular disease to evaluate risk factors and outcomes as well as establish accurate demographic information.

Why is a patient registry important for the moyamoya community?

In rare diseases, there is often less known about the natural history of the disease and there are fewer patients to engage in research at any given hospital or research institute. By combining the data in one cohesive system, we can learn more about the disease and make stronger observations about outcomes.

We are finalizing the registry now, but we will be engaging the patient community when it goes live! So please stay tuned for that!

Moyamoya Patient and Family Support

Part of the Moyamoya Foundation mission is providing assistance to families/patients undergoing moyamoya treatment for expenses not covered by insurance. Since our foundation does not have a means to identify and vet families/patients who have such needs, we have been working with hospital clinical social worker teams. These teams are embedded with the neurosurgery teams and help patients and their families navigate difficult life situations including financial matters.

Early this year a clinical social worker in Boston MA identified a need for a low-income family who was losing income while supporting a child in the hospital with moyamoya. Due to an extended stay and the lost income, the family needed assistance to cover rent and an electric bill for a month. We successfully worked with a clinical social worker to provide the needed support and worked directly with the landlord and electric company to cover the expense.

We are currently working with another clinical social worker in Worcester, MA to help a hearing impaired moyamoya patient obtain communication equipment, which is not covered by insurance.

We are proud to be able to financially help patients and their families directly. Yet, we feel strongly about providing these funds fairly and responsibly. Our goal is to help as many patients as we can. Yet we need your help. We ask that you consider making a donation to our foundation and/or ask for you to share any social worker contacts you may have. As we continue to grow, we hope to build our network of hospital social workers to help us identify patients. The more we know, the more we can help!

Fundraising

Third Quarter	2021	2020
Total Donations, Sales and Non-Donations	\$8,202.36	\$5,540.72
Total Administrative Expenses	\$1,036.60	\$582.10
Total Fundraising Expenses	-	-
Total Program Expenses	-	-
<i>Change in Net Assets</i>	\$7,165.76	\$4,958.62

Board Treasurer, Wes Warren III Comments:

It's great when you look at your 'look-back reports' like quarterly year-over-year and see how much support we received over the past three months compared to the previous year.

The foundation had a stellar third-quarter, with a record high change in net assets!

Full Year	2021	2020
Total Donations, Sales and Non-Donations	\$21,232.09	\$31,868.07
Total Administrative Expenses	\$2,460.45	\$2,746.22
Total Fundraising Expenses	-	90.66
Total Program Expenses	\$12,817.14	\$11,104.50
<i>Change in Net Assets</i>	\$5,954.50	\$17,926.69

Board Treasurer, Wes Warren III Comments:

The foundation continues to battle the economic reductions in disposable income from the country. That being said, I am proud of our Board of Directors for issuing more grants in 2021, despite lower sources of donations and income.

The future is looking good for the foundation. The board of Directors continues to look into new ways of generating more donations, fundraising opportunities and support for our missions.

There are a number of different ways you can help!

You can donate directly [through our webpage](#)

If you want to host your own fundraiser, [Check out our Tiltify!](#)

Do you have any Moyamoya related events? Do you want to share your story? Looking to join the Moyamoya foundation? [Reach out!](#)

If you'd simply like to learn more, there is lots of information available on our webpage <https://moyamoya-foundation.org/>!

Enjoy a few more pictures from our Moyamoya Disease Seminar and we'll talk to you in the next newsletter!

