

KIF1A ORGANIZATION

# KIF1A.ORG Grows and Connects a Global Community

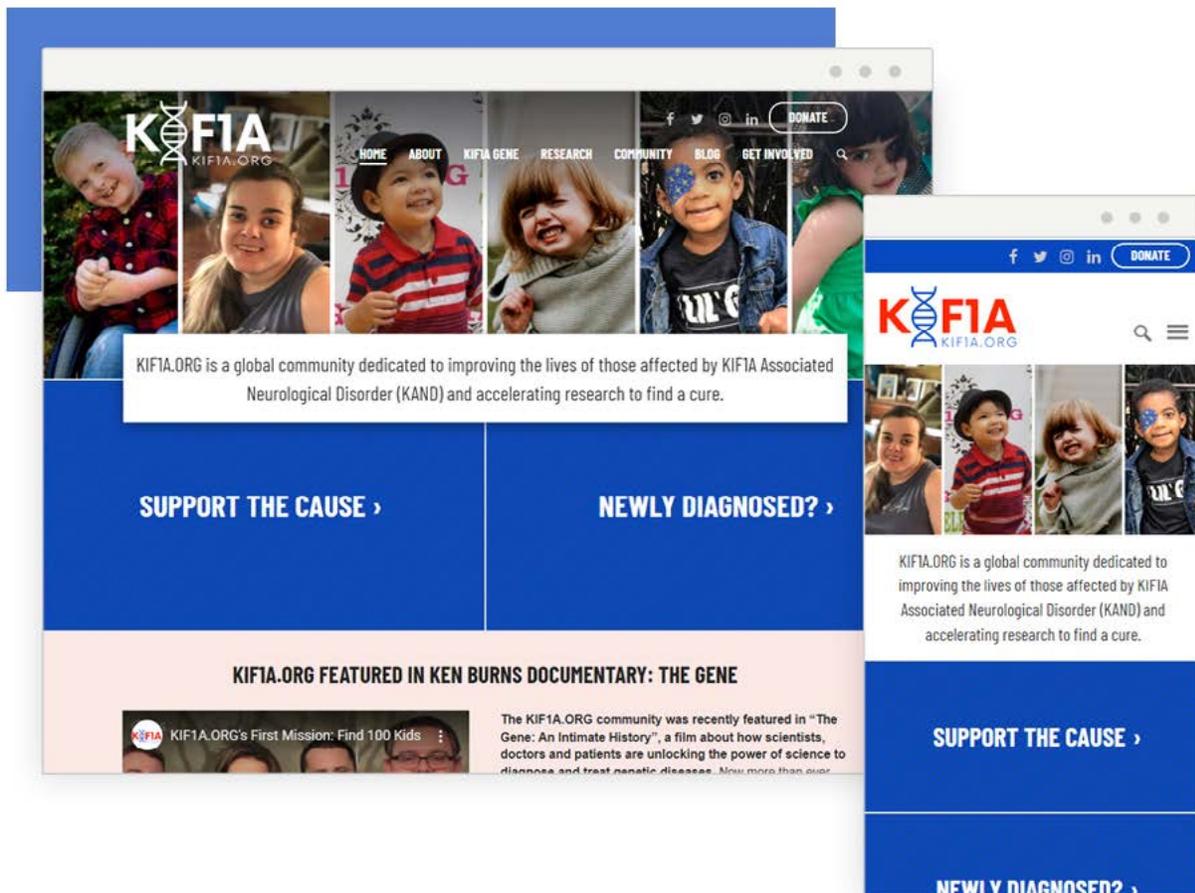
Small organizations with big dreams and a driven group of volunteers powering their mission are not in short supply. This is especially true for nonprofits working in the rare disease space that are looking to connect a global, yet dispersed community. It's often difficult to spread awareness and gain the momentum and funds necessary to drive research for treatment and a cure.

But, a powerful website can change all of that, serving as a hub for your supporters, education and fundraising efforts. Using a strong web presence, KIF1A.ORG has managed to grow their funds, staff, community and research in the past year.



“The functionality of the new site has enabled us to more efficiently connect with our growing community and tell our story in a much more powerful way.”

– KATHRYN ATCHLEY, *PRESIDENT OF KIF1A.ORG*



# KIF1A.ORG: A Small Nonprofit Fighting a Rare Disease

KIF1A.ORG works to improve the lives of families affected by KIF1A Associated Neurological Disorder (KAND) by driving research for a cure. They connect a global network of families, medical professionals and researchers to share knowledge and processes to move their mission forward.

## The Challenge: Convincing the World to Care

KIF1A.ORG has a remarkable but difficult story to share. KAND is an incredibly rare genetic neurological disease that's hard to diagnose and has just about 300 documented cases around the world, although experts believe there are tens of thousands undiagnosed. The previous KIF1A.ORG website was challenging to use for both the nonprofit's team of volunteers and for their community. The navigation was not streamlined and their blog, where they shared ongoing updates, was on another site entirely.

They wanted to connect and build a network of families, researchers and medical professionals, but did not have an easily navigable hub to direct people. And on top of that, they had limited internal capacity without any paid staff members. A dedicated group of volunteers with children affected by the disorder would meet for calls after their kids went to bed.

KIF1A.ORG realized they needed a new site to better support KAND-affected families and raise funds and awareness for their cause.



“ I am not a web developer, but I don't need to be one if I have a partner like Wired Impact who can create a platform and teach me how to easily manage it on my own, but then still be within easy and quick reach if I need help with something.”

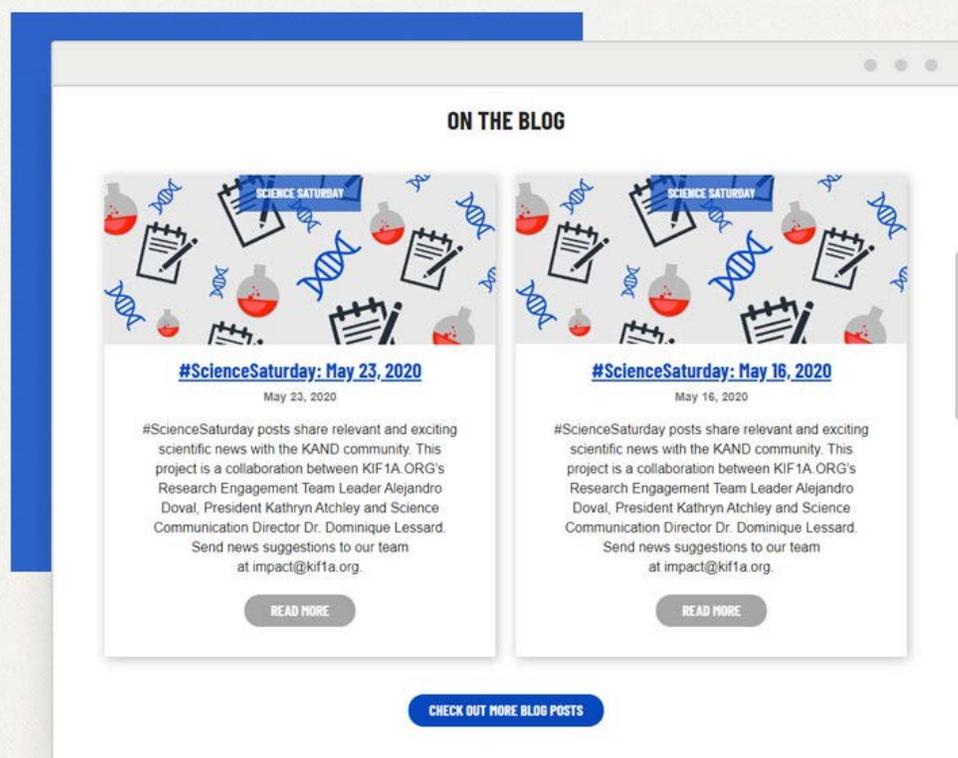
# A Website to Power Growth

Wired Impact partnered with KIF1A.ORG on a new website using our Pioneer design, along with an add-on service for a complete website build out. We launched their new site in 2019 with the goal of providing a central gathering place for their community and increasing online donations.

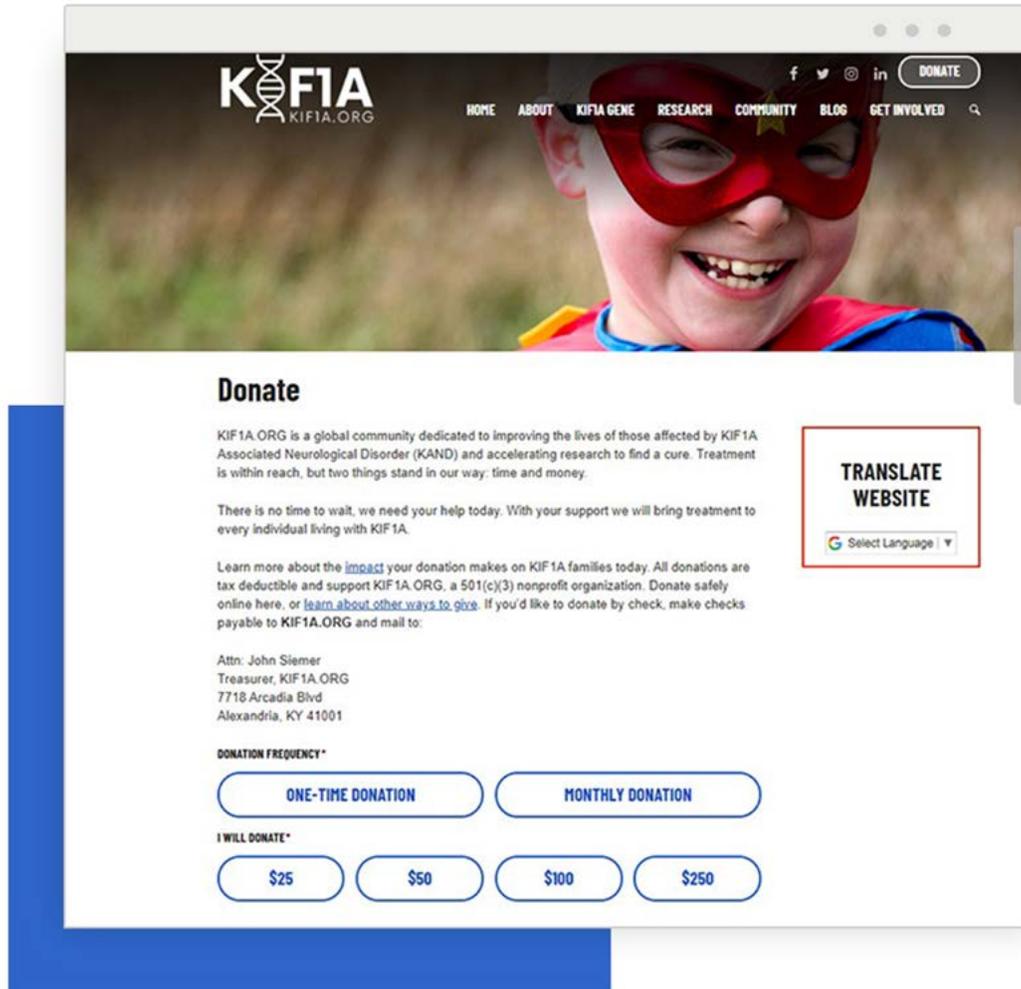
With approachable and heartfelt website content that puts their KIF1A superheroes front and center, the website was able to break down the complicated neurological disorder so that anyone can understand. Its logical website structure made it easy to navigate and find the information you're searching for.

When it comes time to share stories, offer timely research updates, introduce new fundraising campaigns or build awareness on the science behind the disorder, KIF1A.ORG has made good use of the blog functionality on their site. The Superhero Stories from their kids and families are especially powerful.

“We have a lot of information to share, and that can be very overwhelming. The blog allows us to categorize and streamline different themes of information ... Each KIF1A patient in our community can have their own page to tell their story. I think that's a really powerful tool for parents to share their stories. It gets the word out there about KIF1A and how it affects their family, and then also communicates why our mission is so important.”

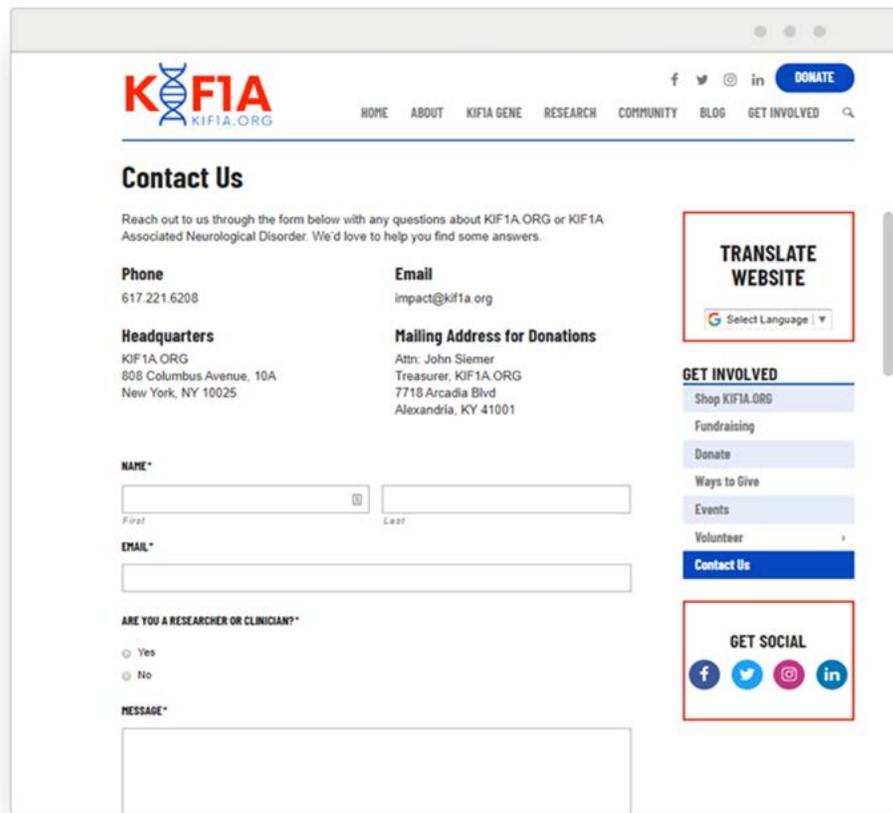


An online donation system was built into their website with a few customizations for their rare disease mission, creating a single place for their team and family fundraisers to send people to give securely. Plus, the powerful system allows them to automate confirmations, virtual donor thank you notes and even send thanks to those who inspire tribute donations.



“The online donation system has been very easy to use and manage, from customizing the donation form to customizing the thank you page and thank you messages that go out to donors.”

Contact forms are a game changer when you previously relied on sprinkling email addresses around your website. KIF1A.ORG was able to use the form builder on their website to create a custom contact form for each of their different audiences: families, researchers and medical professionals. Submitting the form turned out to be a much lower barrier to entry for reaching out than sending an individual email. When you're trying to build a community, simplifying the outreach process is huge.



To promote big annual events like the KAND Family & Scientific Engagement Conference and KIF1A Day, as well as smaller one-off events, KIF1A.ORG appreciates the power and flexibility of the event system built into their site. Promotion, registration and communication are made easy, which is key for events with lots of details to manage.

# Results

In the first year of their new website, KIF1A.ORG was able to accomplish a huge amount of growth. They increased donations, peer-to-peer fundraisers, grants and research projects. They hired their first two full-time staff members. They grew their network, deepened community connections and spread awareness.

**300**  
families  
represented

**521**  
online  
donations

**46,000**  
website  
sessions

**302**  
email  
sign-ups

# What's Next?

Things are constantly being propelled forward at KIF1A.ORG. Their staff, volunteers and entire community of families are strong and driven to find a cure. According to Kathryn, “Our relentless drive to find treatment for these kids who so desperately need it is what has generated all of this success.”

After hiring Kathryn as full-time president, she and KIF1A.ORG co-founder Luke Rosen were able to apply for and receive a \$450,000 capacity-building grant through the Chan Zuckerberg Initiative’s Rare As One project. With the grant, they hired their second full-time staff member, Dr. Dominique Lessard, as Science Communication Director. The grant is a game changer for KIF1A.ORG, moving them that much closer to their mission of finding a cure.

While it’s currently on hold due to the pandemic, KIF1A.ORG is also planning for another conference to connect their communities of scientists and families. And, to celebrate KIF1A Day recently, they dropped dozens of Superhero Stories on their website, which propelled the corresponding fundraising campaign.

Visit the KIF1A.ORG website to learn more about their mission and how to get involved. We’re proud to support them as they work toward a cure for this rare disease.



## Start Your Nonprofit's Path to Growth

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Creating an effective online presence is an important part of raising awareness of your cause and motivating people to act. See how a Wired Impact website can help launch your nonprofit to the next level.

[EXPLORE OUR APPROACH](#)