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IFCR: Leading the Way

Stellar content, targeted outreach and revitalized positioning strategy transform non-profit into world leader

A Case Study

BIG BIRTHDAY COMING UP

The International Foundation for CDKL5 Research was getting ready to celebrate their 10th anniversary. They had begun as a small group of parents of children with a rare genetic disorder. Now, after 10 years of hard work, they led the world in developing CDKL5 Centers of Excellence and advocating for the CDKL5 community.

The IFCR wanted to show how far they'd come – and how hard they worked to advocate for the CDKL5 community.

The trouble was, they had spent 10 years so focused on CDKL5 that they had forgotten to let people know about IFCR. They brought me in to help them shine a light on the amazing work they do and all that they had accomplished.

“Jennifer’s background in healthcare really helps. You don’t even know where to start when someone has no background in it.”

– IFCR Treasurer Amanda Jaksha

SETTING THE PATH

Right off the bat, I saw that **they needed help tooting their own horn**. They had done phenomenal work over the years – but a sizeable portion of the CDKL5 community didn't know of their role in sponsoring research or establishing the Centers.

When I saw their website, I got a clue as to why.

Their website provided information about their rare disorder – just like any other parent-led group. But it buried the bits about creating Centers of Excellence and sponsoring CDKL5 research. In the same vein, they had a lot of helpful and supportive information for CDKL5-affected families – but nothing that set a standard.

“You captured everything so quickly.”

– IFCR President Karen Utley



UNEARTHING DIAMONDS

It was easy to see what this community needed – in-depth information on CDKL5 Deficiency Disorder. I helped IFCR see the need to go beyond their CDKL5 FAQ page and create the kind of content a parent of a newly-diagnosed child would want.

I outlined five guides: *CDKL5 Guide for New Parents*, *Finding Your New Normal*, *Medical Advocacy*, *Educational Advocacy* and *Transition to Adulthood*. **My team interviewed numerous parents and created the world's first in-depth guides on living with CDKL5 Deficiency Disorder.** I then created targeted landing pages for each guide, which made it easy to share them on social media and via email. The landing pages also created an opportunity for IFCR to capture the email address of everyone who downloaded a guide - and that increased their donor base.

“Jennifer helps us see what people are looking for.”

– IFCR Treasurer Amanda Jaksha

Even with great content, though, I knew we had to do something about their website. While it had a ton of information on it, it was hard to find anything. Worse, there were several situations where multiple pages said the same thing, adding to the confusion. It badly needed organization.

Luckily, creating clarity out of disorder is one of my talents. I combed through their website page by page, analyzing menus, sidebars and duplications. Then, armed with an enormous 6-page task list, I brought their website under control. When I was done, they had a crystal clear website that was easy to navigate. Now everyone could find what they were looking for.

Of course, there is no point in revamping a website and creating world-class content unless you have a way to share it with people. When I started, the IFCR hadn't gotten a newsletter out with any regularity in nearly a year. I created a **simple newsletter schedule and template** for them to use each month, so they could stay in touch with their community.

Finally, I crafted **talking points** so every member of their Board would know what to say to the press or when representing the IFCR at conferences. I made it easy for everyone to emphasize their strengths and keep consistent on IFCR's message.



RESULTS

We were blown away by the results!

Our very first campaign was for #GivingTuesday. Once I learned that children with CDKL5 Deficiency Disorder frequently stay up for over 24 hours at a time, I knew we had a theme everyone could relate to: tired parents. So I crafted a “#SkiptheCoffee” campaign for social media and email, which landed them a **whopping 324% increase** from previous years.

"It was the biggest engagement I've ever seen on an IFCR Facebook post." - IFCR President Karen Utley

And within a week of releasing the *CDKL5 Guide for New Parents* and *Finding Your New Normal*, they got an **unprecedented 68 downloads**. Talk about proof-positive that those topics I'd recommended were filling a void!

Best of all, by 3rd quarter, they were already **on track to exceed** their revenue goal for the year.

Just in time to celebrate their 10th birthday!

