

THYROID CANCER CONSIDERATIONS FOR THE 21ST CENTURY SURVIVOR

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INTRODUCTION

For 10 years now, I've been a survivor. I was told I had papillary thyroid cancer at 12 years old. Sitting down in my living room with my family, I wasn't quite sure what to think.

Now at 22, I'm still not always sure of what to think, but I am sure of what I know and experienced. I know we need to change the way we talk about and advocate for thyroid cancer survivors. I know there is a better way for doctors to tell me that I "got the good one." I know I am tired of feeling guilty for having disruptive common symptoms which come with losing your thyroid.

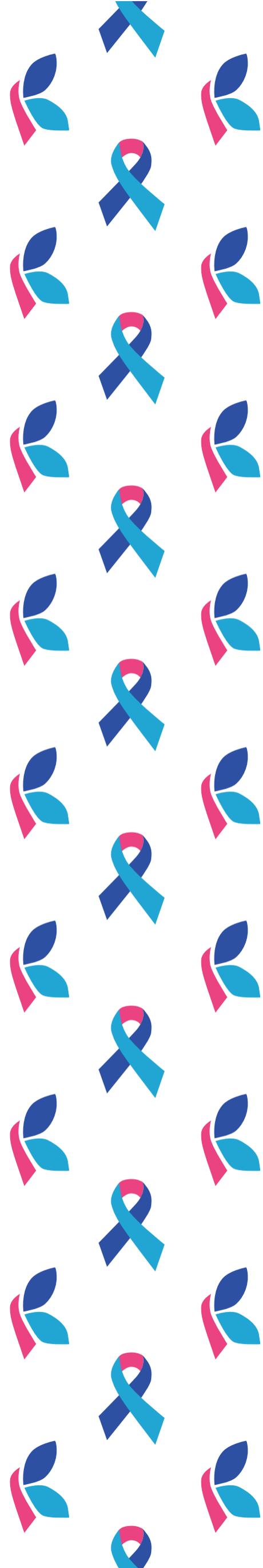
As a survivor, we don't need to feel better about having cancer, but instead feel more supported and represented after the cancer is gone. Being a thyroid cancer survivor is a lifelong responsibility. As a child, I naively thought this would all go away. Cancer never crossed my mind until the night before I had to go back for appointments and blood work.

I realize now there's no going back to the way things used to be.

I also see the changes we need to make as a community. I believe if thyroid cancer survivors are supported with more, thoughtful survivor-focused awareness, advocacy, and understanding, they will be able to improve thyroid cancer education, become their own advocates, create a national community, and create change in medical and social fields.

For the country's most rapidly increasing cancer, we must do better.

-Chloe McElmury



THE “GOOD” CANCER

Although most types of thyroid cancer are nearly 100 percent curable, surviving with it is a lifelong ordeal. Many thyroid cancer patients are misleadingly told how their cancer is better than others, invalidating the perpetual rollercoaster of living with it.

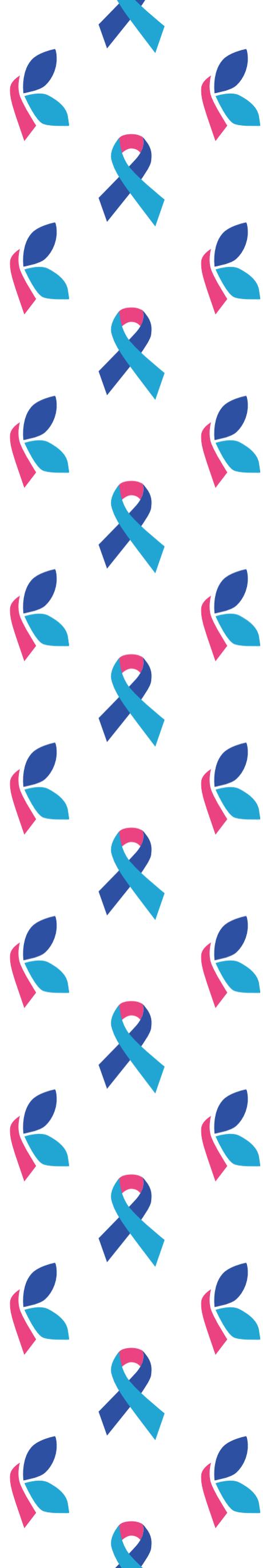
Telling me my cancer is better than other cancers has never made me feel better.

Sure, I’m thankful, but I also know that it will never end. I don’t know if I’ll ever find a doctor who understands me. I don’t need to be reminded how I got the “good” one, but instead how I can live a healthy life as a survivor, navigating and deciphering what that all means.

I’m not the only one—I’ve heard many people online talk about how they feel. How they’ve tried everything but their hair is still falling out. How their doctors don’t listen or believe their symptoms.

I’ve witnessed that thyroid cancer is not the “good” cancer in the slightest.

In a 2013 Canadian study, Easley, Miedema, and Robinson¹ focused on how thyroid cancer is referred to as the “good” cancer. Many who become diagnosed are told at one point or another that they got the “best” cancer to get, because it is so treatable.



**“EVERY
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THE “GOOD” CANCER | Chapter One

This study specifically asked young survivors who were one to five years post-treatment about their experiences with follow-up care and support.

Easley, Miedema, and Robinson reported that, “Every participant mentioned that having the good cancer was a paradox”¹. As a result, this research was able to shed light on realities of living with thyroid cancer. The study was able to conclude that, “The participants in the current study knew that the survival rate for thyroid cancer is good, but as a result, they felt that negative psychological effects often were overlooked”¹. Because of this unique paradox, thyroid cancer patients and survivors frequently feel that their needs aren’t being completely addressed.

Organizations like ThyCa and the Light of Life Foundation have stepped in to provide education and resources where the medical field as a whole just couldn’t. For example, ThyCa has plentiful resources available in many languages. They’ve been able to fill in knowledge gaps and support the thyroid cancer community in ways that doctors couldn’t. However, I believe that these communities, which were started by survivors and with a survivor need, have lost the power they could have.

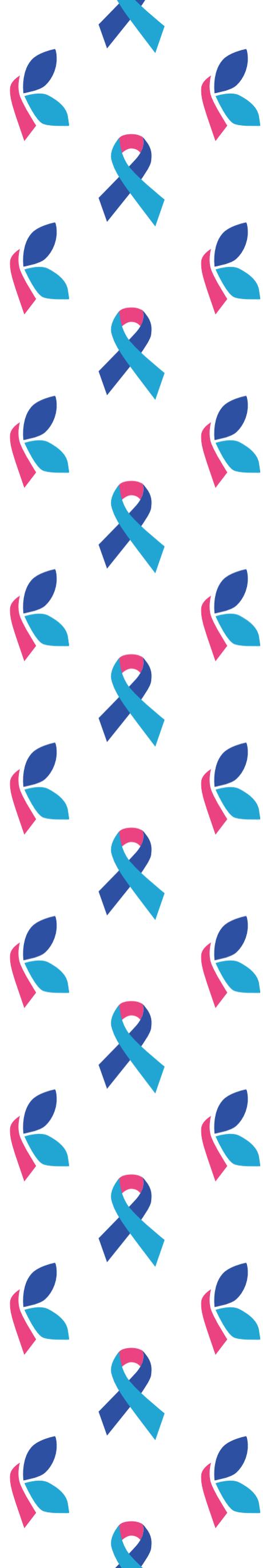
ORGANIZATIONAL SHORTCOMINGS

Thyca and the Light of Life Foundation place a lot of focus on thyroid cancer prevention. They might have some resources on what lab tests to get *after* your cancer is gone, but that's where it usually ends. On the rare occasion we do get more than that, it's usually not as well-made nor visually appealing as it could be.

They have many materials focused on the "before"; they have prevention tips, swallow tests to check for unusual lumps, and reminders to check your neck. I see the value in these, but since we don't completely know what causes thyroid cancer yet, I want to see more attention paid to the survivorship aspect. The high-quality materials about what happens years and years after becoming a survivor are scarce. More likely than not, you'll be a survivor longer than you'll actually have cancer for, so why not focus on that?

Current resources and advocacy materials aren't focused on what happens after cancer is gone and the doctor visits become less frequent.

They don't talk about how your hair might thin and fall out, or how you'll need bloodwork done for the rest of your life. There aren't posters explaining the fear of thyroid cancer returning. Current branding doesn't explain to patients they might feel depressed or have trouble concentrating



ORGANIZATIONAL SHORTCOMINGS | Chapter Two

if their thyroid medication isn't at the right dosage. I shouldn't have to say how important it is to see these aspects of thyroid cancer survivorship represented.

Looking at current thyroid cancer branding, I find it hard to be excited about girly butterflies or cheesy graphics. Sure, these might be your cup of tea (which is great!) but I think we can do better. I want something I would be proud to wear or slap on my laptop for all to see. I want something that even someone with *no relation* to thyroid cancer would still be interested in wearing or supporting. I've never identified with any of the current thyroid cancer branding nor felt the desire to publicly display my survivorship through stickers or t-shirts.

Even more importantly, I want something that addresses people. That addresses the wide range of people who have to fight thyroid cancer.

The purple and pink butterflies were (kind of) cute when I was a little girl, but as a young woman, I want something different. I want *more*.

Thyroid cancer can do better than blue backgrounds for boys and pink for girls, as seen in poster campaign work. Searches online for thyroid cancer will eventually produce some flyers about checking your neck, with a tie and blue background for the male-g geared poster, and pink for the females. As thyroid cancer affects more women

ORGANIZATIONAL SHORTCOMINGS | Chapter Two

than men, much of the content currently on the internet and made by organizations is marketed towards girls. Graphics with sayings like “I fight cancer like a girl” are combined with thyroid cancer colors (pink and purple) to make gendered content.

This excludes men, who *can* get thyroid cancer, and do! Although there have been male-specific campaigns for thyroid cancer awareness, the amount of male-centered awareness is still greatly outnumbered by feminine advocacy. Why can't we appeal to both at the same time? I believe there is a more gender-neutral approach to thyroid cancer survivors to be had.

We need a united, thyroid cancer survivor front. For the most rapidly increasing cancer, we must create purposeful materials and inclusive imagery with visual rhetoric, or the way we talk about thyroid cancer survivors visually, in mind. I believe there is a better and more powerful way to present this life-long affliction than gendered, poorly-made, repetitive branding. This change has to begin with a cohesive and strategic visual messaging plan, leading to a survivor-informed visual system to guide, support, and inform.

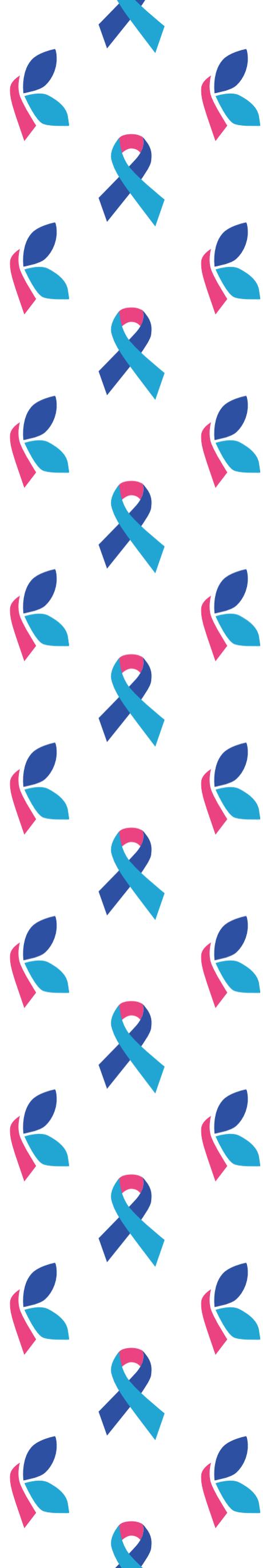
EXISTING DIGITAL ADVOCACY

The shortcomings of thyroid cancer organizations have given way for digital media users to create their own narratives and advocacy. User-created advocacy materials highlight the unmet needs and wants of the thyroid cancer community, despite typically not being professionally made. Materials usually fall into one or more of the following categories: satirical, feminine, or branded content.

Thyroid cancer's paradoxical nature has led to honest truths from survivors in the form of memes and other digital content. We can see this come to light through satire.

Memes are used to showcase shared experiences, such as having to wait an hour to drink coffee after taking your thyroid hormone prescription. If you're a survivor, I'm sure you've seen some of the satirical images online that are really relatable.

I think this satire is our way of taking back ownership of our cancer, experiences, and struggles. You don't see big thyroid cancer organizations talking in this way. Everything from them is hopeful and positive. I've heard a lot from people who say thyroid cancer is the best thing that ever happened to them, and that it taught them to appreciate everyday beauty in our world.



**“REAL
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EXISTING DIGITAL ADVOCACY | Chapter Three

However, it doesn't always feel this way and real cancer isn't always hopeful. We've had to compensate in this area because of that, which is where I believe all the satirical content has come from.

Another type of advocacy we've been making, which isn't exactly positive for all, is very gendered and feminine content. Since society has started aligning with more gender neutral language whenever possible, it's important for cancer to start down this path as well. I think because the thyroid is shaped like a butterfly and that's a symbol we use to refer to it, it's become a catalyst for femininity to spread its wings. Although for some this isn't a problem, the overly-feminine content that's out there could be different— be better.

I believe this type of content can be damaging to the male thyroid cancer experience, as well as a little too niche to appeal to the broad range of thyroid cancer survivors. Because thyroid cancer can affect anyone, at any age, we should more actively be creating content to fit a broader audience. We can't please everyone, but shouldn't we try?

Lastly, the thyroid cancer advocacy online is heavily branded and similar to each other. I already mentioned the butterfly symbol, but there's a little bit more that gets included into the thyroid cancer "brand". Teal, blue, purple, and pink are rampant in online searches; the colors of the thyroid ribbon include a combination of three of these colors, although not always in a consistent

EXISTING DIGITAL ADVOCACY | Chapter Three

way. Sometimes the cancer ribbon is teal/pink/blue and other times the blue is swapped for a dark blue-purple. Even though there are little inconsistencies here and there, it's obvious that the thyroid cancer community is eager for some sort of clear identity that shows the world who we are.

Thyroid cancer as a whole needs unity with consistent colors, recognizable aesthetics, and a clear message. So many out there are eager for thyroid cancer content, whether that's apparel or stickers. However, we must be thoughtful in our approaches and designs.

THE SPACE FOR SOMETHING NEW

The goal of thyroid cancer organizations should be a unified, modern identity that appeals to the general public, while also appropriately serving and addressing thyroid cancer survivors. While this is a monumental task to undertake, I believe it's completely possible.

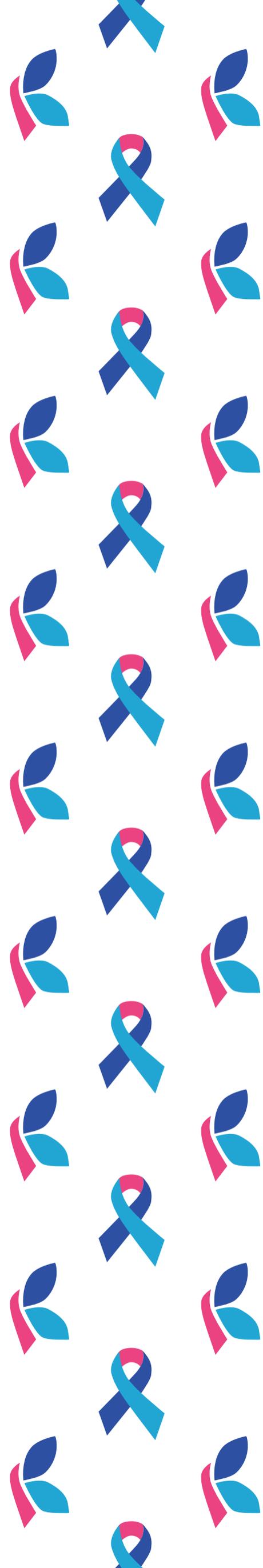
We need a thyroid cancer organization that clearly lays out what it's about, and sticks to an easy-to-follow mission to more accurately represent thyroid cancer survivors. We can do this by increasing thoughtful awareness, advocacy, and understanding.

This is all why I started thyCAN survivors. The paradox of thyroid cancer being so curable *yet* lasting a lifetime leads to informational and emotional needs not being met.

They must be addressed.

ThyCAN is a place where *real* stories and experiences are shared. I believe in honesty, and thyCAN is as honest as it gets. We are about sharing relevant facts and statistics, educating survivors and the public, and sharing the real highs and lows from survivors.

Through thyCAN, I hope to educate the general public, while also providing a space for survivors to feel wholly represented in order to begin to make real change in social and medical communities.



NOW WHAT?

**You can find
thyCAN survivors on:**

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