

EXECUTIVE SUMMARY

Evaluation of the Prevent Blindness Art Therapy Program and Its Impact

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Prevent Blindness

Art Therapy Program

Purpose

The Art Therapy Program, which launched in the spring of 2022, is for people living with Thyroid Eye Disease (TED) and their care partners. In January 2024, four focus groups were conducted with past program participants to learn about the impact the program had on them and to gather recommendations that can assist staff as they continue to offer the program.



Joining the Art Therapy Program

Participants varied in how they first learned about the program. Ways included scrolling on Instagram, internet searches, word of mouth, and information provided by a Patient Access Liaison (PAL) at Horizon Therapeutics [now Amgen]. They often joined the program not knowing what to expect.

“I had nothing to lose [by joining the Art Therapy Program] and I gained so much. I found the conversations were meaningful and really truly people were connecting.... [The Art Therapy Program] was so uplifting and affirming... It was so validating. I don't know if I created any art worth keeping, but I sure appreciated the connections.”

Impact of the Art Therapy Program on Participant's Emotional Well Being



The program provided an opportunity for participants to hear from others impacted by TED and to share the journey in a safe space.

“[Participating in the Art Therapy Program] gave me perspective and the broader sense of getting to know others [with TED] without the trauma bonding that I could see happening in other forums. There was room to have a whole range of emotions.... It was overwhelming positive energy without that, let's find the silver lining. Sometimes there isn't a silver lining. Everyone was still a positive person.”



Participants

The eleven participants were from seven states. six out of ten of the participants had been diagnosed with TED within the last five years. All had participated in the Art Therapy Program between Spring 2022 and Fall 2023.

The 11 Art Therapy Program Participants:

10/11 had TED | 1/11 was a care partner



4/11 had little or no art experience



3/11 some art experience that was not formal



2/11 some formal art experience



1/11 was an artist

The program assisted participants in becoming more comfortable sharing their experience with TED with others.

“Before art therapy I was embarrassed and didn’t talk to anyone about my eyes. Before Tepezza I would pretend TED was not there if someone said something about my eyes. Now when people ask, I have no problem explaining I have an autoimmune disease. I don’t hide it anymore. I did before art therapy.”

The program’s therapeutic value was recognized.

“The program impressed me. I was overwhelmed by what I got from it. The creative aspect was very therapeutic. There were times I’d tear up seeing what other people created. The explanation they provided of what they created was very therapeutic.”

The program did cause some participants to experience a range of emotions.

“I am looking at all the people in [*the session*] and realize when they look in the mirror [*they also*] see changes to their face. It was good to know that we’re all in this together but at the same time it was a little scary because there were people who had more problems and surgeries. They had struggles. It made me feel grateful because I didn’t have some of the struggles they had.”

The program changed the long-term outlook of some participants.

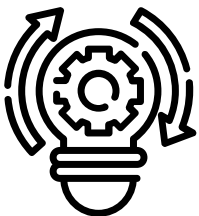
“I feel more hopeful in general. [*The Art Therapy Program*] really lifted me up. [*Before the program*] I was isolated, and I felt this lift and desire to keep moving forward.... I felt hope and that has remained. I still have bad days and bad weeks, but overall...I haven’t felt as grim as I did initially. [*The benefit of the program*] was huge for me emotionally.”

Ways the Art Therapy Program Supported Participants in Having a Voice



- Providing knowledge to better explain TED symptoms to others.
- Using art to spark conversations about TED and its impact on the individual.
- Supporting those with TED and their care partners who attended the program, together to better understand each other’s perspective.

“The program has allowed me to share with [*doctors*] how [*TED*] impacted me. I tell them I don’t enjoy going to soccer with my kids, so what can I do to make it better? It has helped me advocate to get them to... understand my TED [*symptoms and how they impact my life*].”



It’s Not About the Product, It’s About the Process

The 11 participants continue to engage with art even though they are no longer in the Art Therapy Program.

“My stuff [*projects completed during the session and postcard created now*] isn’t impressive. It is not about making something that looks great, that wasn’t the point of the program. I got the therapeutic part which was great.”

The Art Therapy Program caused participants to view art through a different lens.

“The art therapy gives you a way to express [*your emotions*]. I didn’t know I would be angry until I got guided through the process – it was cool to see how it has changed me. I truly enjoy art now. I was callous about it before.”

The art directives served as a vehicle to face the emotional toll TED takes on the individual.

“The scribbling exercise prompted me about how sad I still felt. You’re just trying to get through the next thing and be positive. I thought I had been acknowledging it [*my feelings about TED*] but that day it helped me grieve for the old me. That exercise did that for me. [*It provided a*] lot of release for me.”

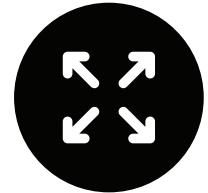


The directive to create a mask showing what you felt on the inside and what you projected on the outside was a powerful catalyst for several of the participants.

“On the inside it was that I keep my feelings hidden and outside is what I show to the world. Inside it was black and a person hiding all by herself. Outside it was flowers and sunshine and blue skies. I project happiness. I didn’t realize how dark I felt inside and alone and small and hidden. [Creating the mask] was impactful. It helped me let it all go and showed me I can be sunshine all the time both inside and outside.”

Recommendations to Continue Improving/Expanding the Program

- More people need to hear about the program. Prevent Blindness should provide information about the Art Therapy Program to endocrinologists, ophthalmologists, and other healthcare providers who treat those with TED. Encourage them to share information with their patients.
- People diagnosed with TED need to hear about the program early after diagnosis. Ask all pharma companies with current or pending TED therapies to inform patients they connect with about the Art Therapy Program. Provide the information early in the treatment process.
- Healthcare professionals should experience the program for themselves. Invite healthcare providers to take part in a session or create a series for healthcare providers. If they see the power of the program, they will be more likely to share information with their patients and their care partners.
- Testimonials would help pique potential participants’ interest. Increase the program’s social media presence and expand the website to include detailed information and examples of art created by participants.
- Participants who join more than one series benefit more. Continue to allow those with TED and care partners to enroll in multiple series.
- Care partners are welcome most of the time, but could use separate sessions, too. Consider having specific sessions only for those with TED or only for care partners.



“[Through the Art Therapy Program] I have connected with other people who have TED. What is a better feeling than connection? When you’ve been searching for that light under the door and then when you’re in the room with everyone, it is so fulfilling.”



[PreventBlindness.org](https://www.PreventBlindness.org)

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