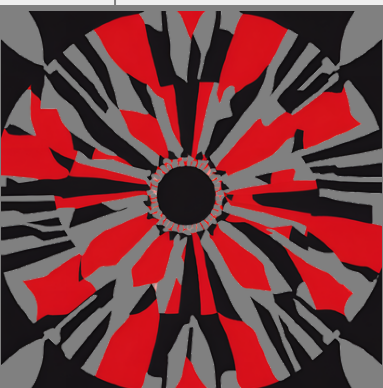
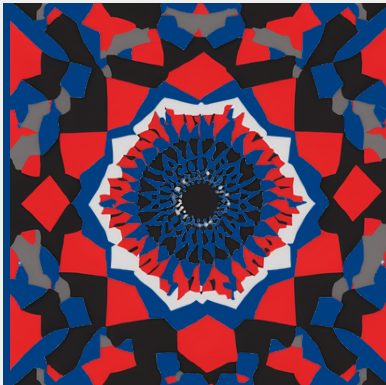


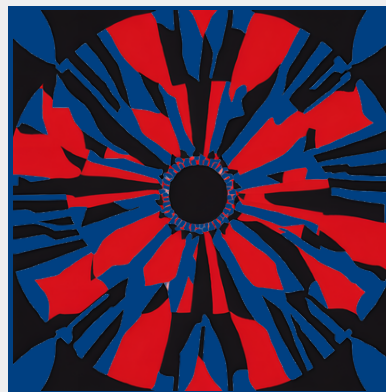
# 2024 Annual Report



**PCVIS**  
Pediatric Cortical Visual  
Impairment Society



Transforming outcomes for  
children and youth with CVI



# We're here to transform outcomes for children and youth with CVI.

Over this past year, we have been experiencing exciting times, a sort of renaissance for PCVIS, a time to refocus, reenergize, and remobilize toward our united goal –transforming outcomes for children and youth with CVI.

In January 2024, you – our PCVIS members – voted seven new members into office as our Board of Directors. You selected medical practitioners, educators, parent advocates, legal advocates, researchers, and therapists and in doing so, selected a Board that directly mirrors the mission of PCVIS, equipped to collaboratively tackle the challenges that children and youth with CVI and their families confront each day.

Since then, we have put our heads down and we have been at work, conducting thorough reviews of our infrastructure and strategic plan, developing leadership for committees for professional development, policy, marketing and communications, finance, and membership sustainability, and we are equipped for a dynamic year ahead.

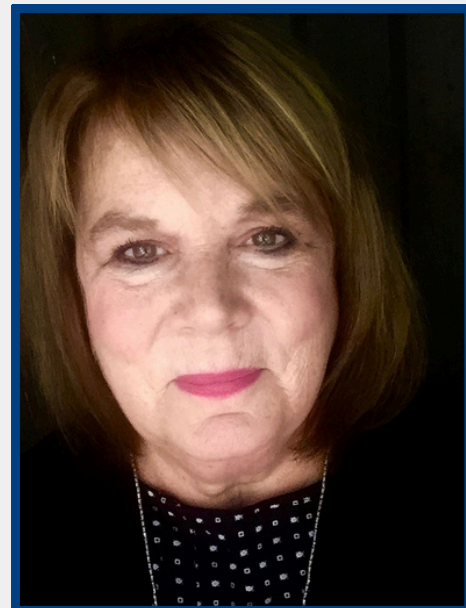
Now, with new air in our sails, we will exercise the strengths of this organization, in areas where we are needed most, such as early screening protocols, advocacy and policy reform for the right to fair and equal access to education, funding for research, and supporting ongoing professional development for educators and clinicians.

With this forward momentum beneath us, we invite all PCVIS members to get involved, join a committee, and together we will continue to break new ground.



**Francesca Crozier-Fitzgerald**

Co-President



**Christine Roman-Lantzzy**

Co-President

# Meet the Board



Francesca Crozier-Fitzgerald  
Co-President



Christine Roman-Lantzy  
Co-President



Jonathan Graves  
Secretary



Melinda Chang



Lynn Elko



Karen Harpster



Kathryne Hart



Lindsay Hillier



Mara LaViola



Sharon Lehman



MaryAnne Roberto



Stephanie Steffer



Mary Zatta



# Celebrating 10 years of CVI Advocacy

For 10 years, PCVIS has engaged in multidisciplinary collaboration and advocacy for children and youth with CVI. It began with a curious clinician and self-described “CVI journeyman.” Over a 33-year career as an ophthalmologist, Dr. Richard “Skip” Legge built his CVI knowledge. Then he built bridges with other professionals dedicated to the cause.

When asked what the future holds for the CVI community he says, “We have to stay the course with the NIH and the NEI. We have to complete the work on the diagnostic criteria, the definitions, and the electronic case registry. And this work benefits the entire CVI community. This is not just about the scientists. This is about everybody.”

[pcvis.vision/pcvis-celebrates-a-decade-of-cvi-advocacy](https://pcvis.vision/pcvis-celebrates-a-decade-of-cvi-advocacy)



PCVIS members (from left) Gunjan Rastogi-Wilson, Al Lantzy, and Anna Ault educate conference attendees about CVI.



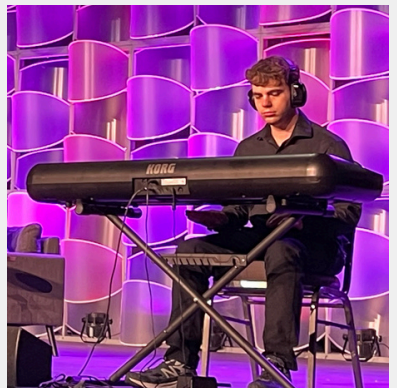
# CVI Celebrations

PCVIS members share **remarkable moments** from 2024.

In February 2024, Lindsay Hillier and a colleague traveled to Nunavut, Canada, to provide CVI assessments and support to families and other professionals. Inuit children have historically lacked access to vital vision services. By collaborating with families and local educators, they hope to create inclusive environments that empower Inuit children with CVI to thrive and reach their full potential. This will be an ongoing initiative to build knowledge about CVI and necessary supports in this very northern territory of Canada.



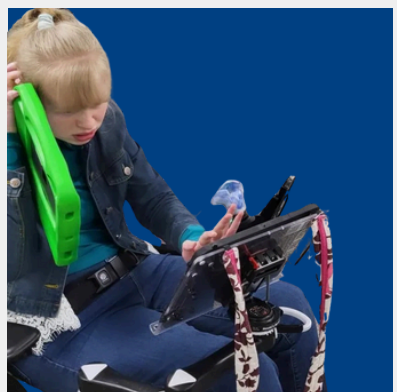
Zach LaViola won a Council of Exceptional Children "Yes, I Can Award" for his music. "I am proud because I work hard to perform and do a good job," he says. "I feel like I am representing all people like me, who have complex support needs. I want to prove to the world that we ALL are capable of doing really great things when appropriately supported, given access, and given the opportunity to do so. My music is my voice and my music is my advocacy. Everyone should have a voice and we all should be valued."



In the short film Acting Normal With CVI, international CVI advocate and opera singer Dagbjört Andrésdóttir shows audiences what it's like to live life and break barriers with CVI. The documentary will be released in 2024.



Communication Science Disorders and Human Computer Interface researchers from Penn State University acquired a two-year grant to develop and test prototype technology that shifts the burden of access from the AAC user to the technologies. The first aim was to bring a voice to body-based communication gestures. Emma, who has CVI and uses AAC, was the pilot user of the biosensor system and through her participation proved out the theory, application, and use. The team, which includes Emma, will present their findings and future research aims at the Assistive Technology Industry Association (ATIA) Conference in January 2025.



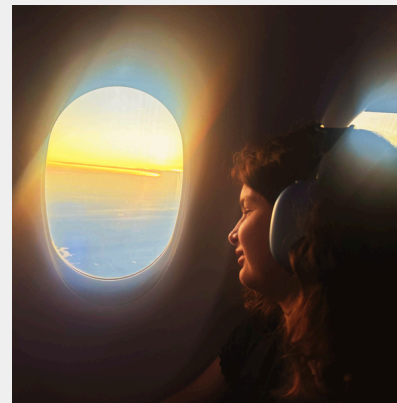
# CVI Celebrations

PCVIS members share **remarkable moments** from 2024.

“This past summer, Krish learned how to swim — like jump into a pool of eight feet of water and go into the ocean and float type-of-swim!” says his mother, Gunjan Rastogi-Wilson. “He has always been scared of water in general — he would swim with a vest, but waves and other children splashing deterred him from really enjoying the water. He didn’t like water in his eyes, he didn’t like that he couldn’t see well since his glasses were off, and he didn’t like that the water had constant movement. I’m so proud of him for working hard to reach his goal! This is a true CVI success story for Krish!”



Pediatric VIEW launched the first CVI peer advocacy group for teens with CVI. Francesca Crozier-Fitzgerald says, “Real Talk: CVI is small and designed to provide a safe, fun space for our young teens with CVI to lean into a supportive team, build confidence in speaking about some challenges they may face due to CVI, and most importantly, develop applicable problem-solving skills to address those challenges.” Participants join the virtual meeting from around the US for one hour, once a month. Topics include: Making and sustaining friendships, using assistive technology, starting conversations, advocating for needs in class and community, navigating new friends’ houses, parties, and tricky social situations.



In just two years, special education advocate Mara LaViola helped 23 children finally receive a diagnosis of CVI and secure vision impairment eligibility under IDEA — life-changing milestones that will open new doors for these children and their families. By leveraging positions on various state-level nonprofits, she’s amplified the message that there is an urgent need for early CVI diagnosis, especially in disability communities where co-morbidity is high and the other diagnosis is masking the visual impairments, such as autism. She says she’s excited to be “gaining momentum in forming a state-level coalition to push forward a groundbreaking bill that will mandate CVI screening for at-risk infants and toddlers — paving the way for earlier interventions and brighter futures.”



## Medical Community

### Creating awareness and funding research

The National Eye Institute and physicians across the US continue their commitment to address challenges related to CVI.

The Trans-NIH CVI Workshop, co-chaired by Melinda Chang, MD, and Lotfi Merabet, OD, PhD, MPH, composed a working definition of CVI and outlined the parameters for a CVI registry.

With diagnostic criteria and data collection, the medical community will be able to diagnose more closely, refine diagnostic batteries, identify meaningful outcomes, and document the scope and prevalence of co-occurring conditions.

The NIH CVI Working Group's paper on the definition of CVI will be published in the December issue of Ophthalmology!

Chang and Sharon Lehman, MD, co-authored an American Academy of Pediatrics Clinical Report on screening for CVI, which should help pediatricians identify and refer patients with suspected CVI.

They hope their efforts will help doctors recognize and diagnose children with CVI earlier so that they can receive services. It will be published in Pediatrics.



# PCVIS Highlights

## OPERATIONS

Hosted monthly board meetings

Hired Executive Director

Changed banks and contracted a registered agent

## STRATEGY

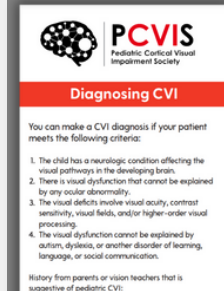


Reviewed and prioritized strategic plan objectives



Established new committees and leadership

## EDUCATION



Refreshed educational cards for distribution

## PROFESSIONAL DEVELOPMENT

Sponsored two conferences: Perkins & Innovations in CVI



## MEMBER BENEFITS

Sponsored four PCVIS members to attend CVI conferences



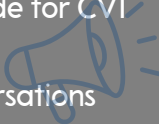
## BRANDING



Created member store with logo merchandise

## ADVOCACY

- Endorsed the EDVI Act
- Created a guide for CVI advocates
- Started conversations with other organizations and legislators



## ENGAGEMENT

Facebook reach: 5.8K



New LinkedIn account with global reach: Canada, Cyprus, US, Brazil, South Africa, India, Australia, Germany

## COMMUNITY



Redesigned membership map and directory

# Financial Overview

Numbers as of September 30, 2024

Consolidated Statement of Financial Position	Income	Expenses
Donations	\$7,335.00	
Membership dues	\$7,257.00	
Sponsorships		\$12,7780.00
Operational expenses		\$1,426.00
Educational & marketing materials		\$1,312.00
Contractors		\$7,438.00

Total Cash                    \$44,402.92

Months of Cash                14 months

on Hand (MOCH)

Best practice: 3-6 months

# Professional Development

## Top 3 initiatives

- Increase awareness of CVI among professionals through presentations at national meetings, including PCVIS as a resource
- Digest and deliver scientific articles about CVI through social media accounts on a regular basis
- Conduct online survey of professionals about their learning needs

## Big audacious goal

Provide virtual professional development opportunities on PCVIS platforms

## Board contacts

Medical subgroup: Melinda Chang, Lynn Elko, Karen Harpster

Education subgroup: Jonathan Graves, MaryAnne Roberto



Advance interdisciplinary education and research

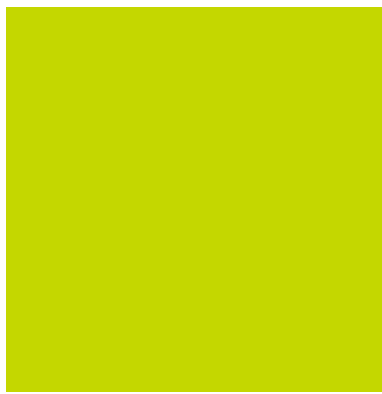


Improve public and professional awareness of CVI in children and youth

Join the  
committee







# Educational Resources

This year we updated our educational print materials to account for new developments in the field of CVI. The flyers make great resources for professionals and families. Hand them to a doctor during an appointment. Share them at IEP meetings. Give them to a family who has a newly diagnosed child. Visit our exhibit table at a conference or find the digital files on our website.

[pcvis.vision/educational-downloads](https://pcvis.vision/educational-downloads)



[What is CVI?](#)




[Diagnosing CVI \(for Medical Professionals\)](#)



[CVI Fact Sheet for Therapists](#)



[CVI Fact Sheet for the Teacher of Students with Visual Impairment](#)



## Diagnosing CVI

You can make a CVI diagnosis if your patient meets the following criteria:

1. The child has a neurologic condition affecting the visual pathways in the developing brain.
2. There is visual dysfunction that cannot be explained by any ocular abnormality.
3. The visual deficits involve visual acuity, contrast sensitivity, visual fields, and/or higher-order visual processing.
4. The visual dysfunction cannot be explained by autism, dyslexia, or another disorder of learning, language, or social communication.

History from parents or vision teachers that is suggestive of pediatric CVI:

- The child interacts visually in a more focused way with an uncluttered workspace and lower sensory complexity.
- The child prefers to gaze at light.
- The child does not respond to people or large objects from across the room.

Behavioral characteristics of CVI in children include:

- Absent or clumsy visually guided motor response.
- Preferential response to a flashing light toy or brightly colored object (usually yellow or red) with ocular following movements.
- Responds more to approaching from other.
- Delayed response to fix and follow on vision.
- Looking up or away

Download resources



# Legislative & Policy

## Top 3 initiatives

- Establish Action Committees in every state
- Draft legislation for early screening and identification of CVI
- Address vision impairment eligibility in every state

## Big audacious goal

Pursue a mandate for offering compensatory services to students with late identification of CVI

## Board contacts

Kathryne Hart, Mara LaViola



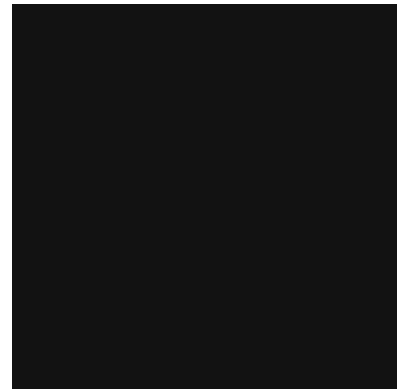
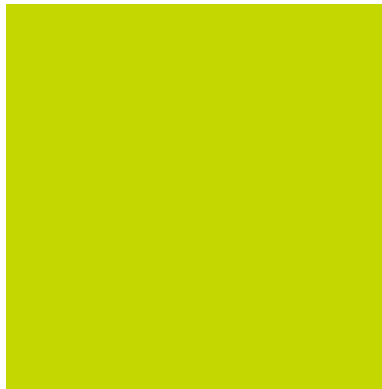
Advocate for governmental policy that improves quality and quantity of vision services available to children and youth with CVI



Advocate for appropriate allocation of resources to allow for improved medical and educational vision services for children and youth with CVI

Join the  
committee





# A Guide for CVI Advocates

Sharing personal experiences can be a powerful catalyst for change. Here's how you can use your narrative to activate legislative changes at the state level, with a special focus on the importance of understanding the political context and building allies across the aisle.

[pcvis.vision/a-guide-for-cvi-advocates](https://pcvis.vision/a-guide-for-cvi-advocates)

1

Know your political landscape

4

Join forces with others

2

Build bipartisan support

5

Propose concrete solutions

3

Share your story and amplify it

Read the guide





# Marketing & Communication

## Top 3 initiatives

- Leverage interests, talents, and connections of committee members to improve awareness of CVI
- Develop an inventory of parent groups, professional societies, government entities, and educational institutions that may impact children and youth with CVI
- Develop press release “package” that can be at the ready to share about PCVIS

## Big audacious goal

New York Times editorial about CVI

## Board contacts

Lindsay Hillier, Sharon Lehman, Stephanie Steffer



Enhance dissemination of information and its communication among and between CVI stakeholders



Improve public and professional awareness of CVI in children and youth

Join the  
committee



# Membership

## Top 3 initiatives

- Explore increasing membership fees
- Identify potential membership levels and determine their benefits (e.g., Pre-Service Student/Graduate Student, Group/Corporate, Family, CVIer)
- Increase membership by 25% by gaining new members and renewing lapsed members

## Big audacious goal

PCVIS Membership will consist of 1000 members which will include varied level of memberships and benefits

## Board contact

Mary Zatta



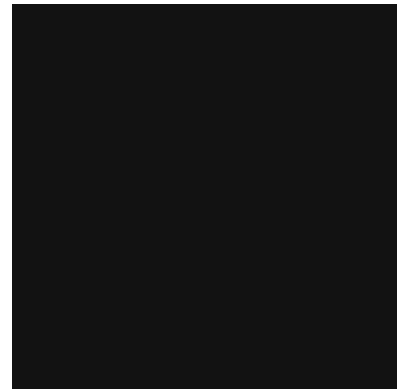
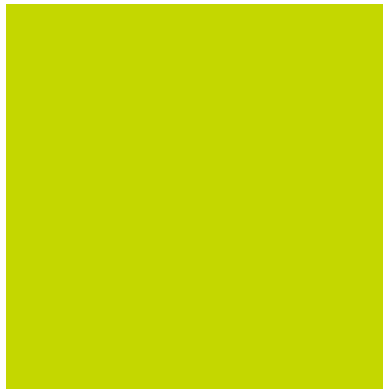
Build our membership base



Engage a growing group of members in the advancement of all strategic goals

Join the  
committee





# Our Members

We are a growing group of physicians, educators, therapists, care partners, advocates, families, and people with CVI. Our reach is extending globally. We are visionaries who see a future where children and youth with CVI have complete access to appropriate medical care, education, and intervention. Won't you join us?

[pcvis.vision/about-pcvis/join-us](https://pcvis.vision/about-pcvis/join-us)



Join PCVIS





# Member Store

Buy PCVIS wear and gear in our Lands' End-hosted store.

These branded items will make a great conversation starter about CVI and our organizational mission everywhere you go! All items will drop ship directly to your address.

[pcvis.vision/store](https://pcvis.vision/store)



# PCVIS at a Glance



A 501(c)3 nonprofit

Pediatric Cortical Visual  
Impairment Society (PCVIS)

Founded in

2014

## Purpose

Our multidisciplinary membership base **advocates for children and youth with CVI**, a brain-based visual impairment and a growing public health crisis.

## Helpful links

- Educational resources: [pcvis.vision/educational-downloads](https://pcvis.vision/educational-downloads)
- Salient Features: The PCVIS Blog: [pcvis.vision/blog](https://pcvis.vision/blog)
- Member store: [pcvis.vision/store](https://pcvis.vision/store)

## Donate online

Federal tax ID (EIN): 47-1752181



## Contact us

[membership@pcvis.vision](mailto:membership@pcvis.vision)



PCVIS.vision



PCVIS.vision



[linkedin.com/company/PCVIS](https://linkedin.com/company/PCVIS)

