



# WHAT TO DO WHEN THERE'S, "NOTHING WE CAN DO."

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# Financial Disclosures

I have no relevant financial relationships to disclose



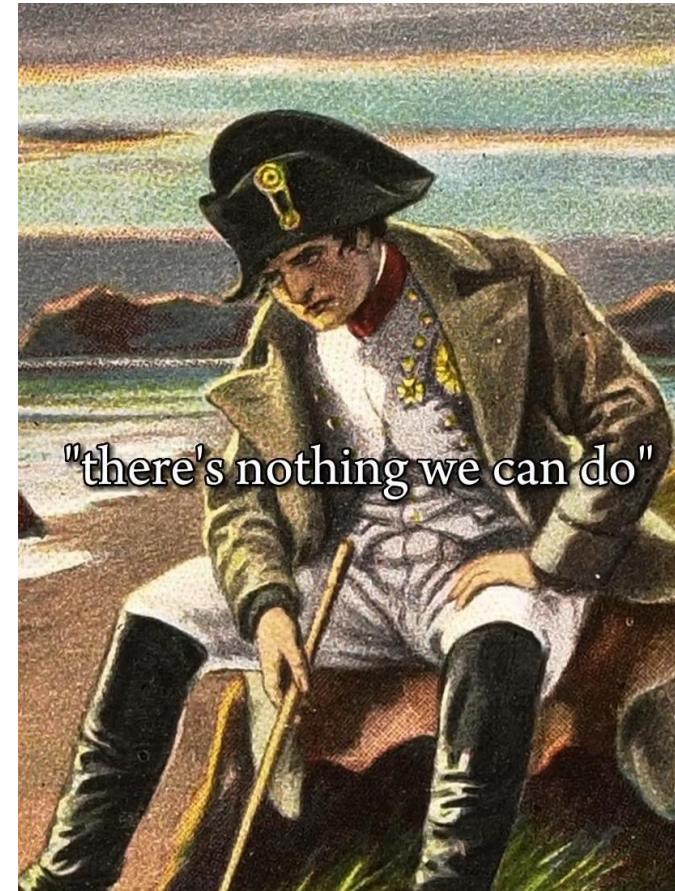
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# Outline

- ▶ What happens when, “There’s nothing we can do?”
- ▶ Genetic Testing
- ▶ Local resources
- ▶ National resources
- ▶ How to find, “Something we can do.”

# Why We Say, “There’s Nothing We Can Do.”

- ▶ No approved medical treatments
- ▶ Time constraints
- ▶ Lack of knowledge
- ▶ Not wishing to give false hope



# What Patient's Hear

- ▶ You don't need to come back
- ▶ Your life will get worse
- ▶ Why bother?



Cartoon by Mick Stevens The New Yorker March 25, 2021

# But Something Can Be Done

Take inherited retinal diseases for example

- ▶ Genetic testing
  - ▶ Confirm diagnosis, prognosis, and any medical guidelines
    - ▶ Chance of *RPE65* mutation
    - ▶ Guidance of things to avoid
  - ▶ Clinical trials
  - ▶ Information for family members
- ▶ Genetic counseling
  - ▶ Understanding and empowering patients



# Local Resources

Options for all

- ▶ Where are the patient's pain points with their vision?
  - ▶ Feeling Isolated
    - ▶ Local Support Groups
      - ▶ FFB
      - ▶ You Don't Look Blind
    - ▶ Transportation
      - ▶ RTD Discount Card
  - ▶ Trouble at work or in life
    - ▶ Low Vision Optometry
    - ▶ Accessible Tech Training
    - ▶ Department of Vocational Rehab



# Colorado Center for the Blind

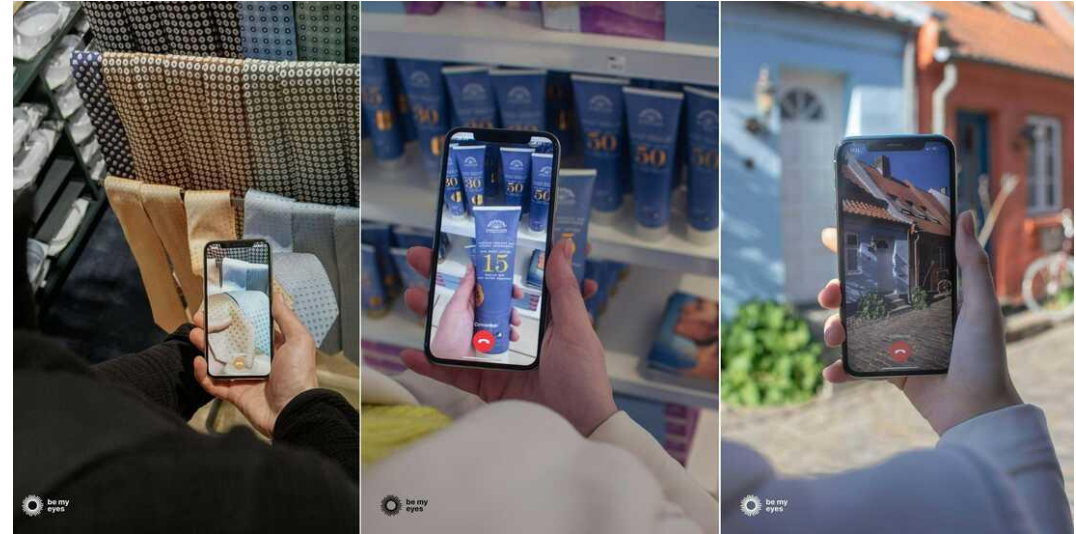
Internationally renowned right here in Littleton CO

- ▶ Independence Training Program (18+)
  - ▶ Six- or nine-month residential program
  - ▶ Typically funded through the DVR
  - ▶ Braille, cane training, home management, and technology training
- ▶ Blind Seniors (55+ programs)
  - ▶ Same services as above
  - ▶ Individualized training to match person's goals.
  - ▶ Weekly support groups (in person and virtual)



# National Resources

- ▶ Education, Research, and Clinical Trials
  - ▶ Foundation Fighting Blindness
  - ▶ National Federation for the Blind
- ▶ Accessibility Apps
  - ▶ Be My Eyes
  - ▶ Color Blind Pal
- ▶ General Assistance
  - ▶ Hadleyhelps.com
- ▶ Mental Health Providers
  - ▶ Psychologytoday and Rula



# Guide Dogs

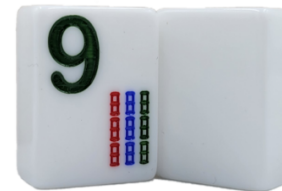
You cannot pet that dog

- ▶ Quick check list for guide dog interest:
  - ▶ 18 years or older
  - ▶ Legally blind with BCVA  $\geq$  20/200 or a visual field  $<$ 20 degrees OU?
  - ▶ Comfortably able to walk one mile and do you have routine routes and outings?
  - ▶ Undergone O&M training?
    - ▶ May be provided by guide dog center
  - ▶ Able and willing to care for physical and emotional needs of a working dog?



# Personalized Resources

- ▶ What's important to your patient?
  - ▶ Quick or not so quick Google search
- ▶ Learn from your patients



HOME / MAH JONGG TILES / VISION IMPAIRED TILES

**Large Print Solid White American Mah Jongg Tiles**

**\$275.00**

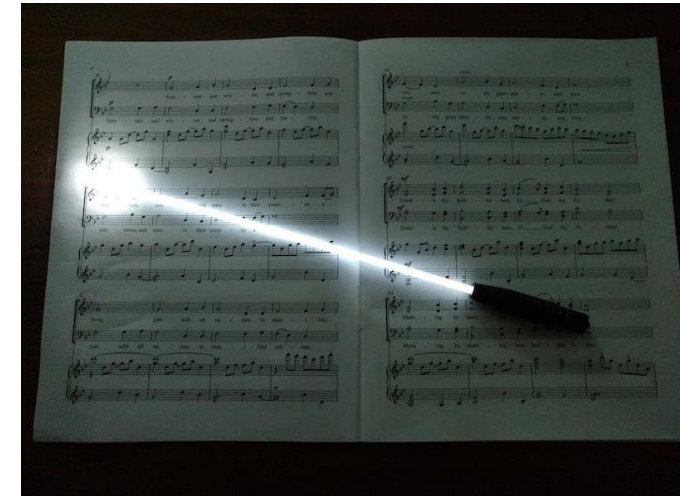
In stock

- 1 +

**ADD TO CART**



Phamly Theater Company



# Keep Learning!

- ▶ Blind influencers
  - ▶ Molly Burke, Matthew and Paul, Lucy Edwards, The Blind Life, asfvision
- ▶ Read blind memoirs
  - ▶ Now I See You
  - ▶ The Country of the Blind
  - ▶ The Beauty of Dusk
- ▶ Ask your patients what they're doing



BlindShell Classic 3 – The Best Accessible Phone Just Got Better



The Blind Life  
82.6K subscribers

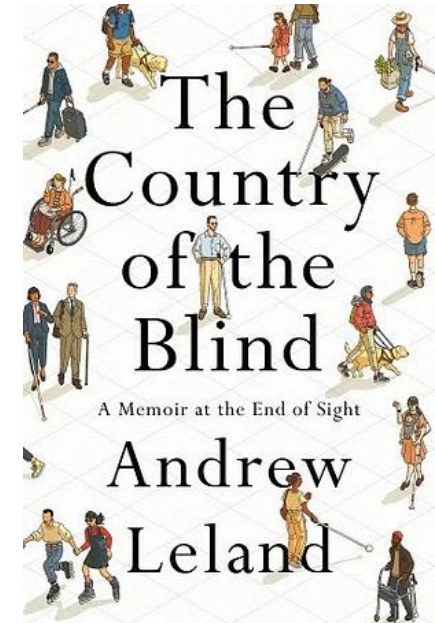
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# Take Home Thoughts



Try, “While there are currently no medical treatments for this condition there are still ways we can help you.”



Think of your non-medical interventions.

- Support Groups and Therapy
- Tech help and training
- O&M or Service Dogs
- Activities



Find what your patient feels they have lost along with their vision. How can you help them find it again?



Never stop learning from your patients and the blind and low vision community



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Thank you!

Up Next: Spotlight on Red Light Therapy

Pre-recorded presentation by Dr. Betty Zhang