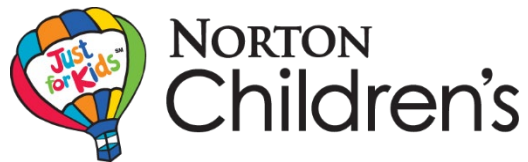



# Change How You See, See How You Change, Positive Exposure The Spirit of Difference

Rick Guidotti  
Corrie Harris, MD





# Learning Objectives

- Discuss ableism/bias and potential health implications of how people with disabilities are viewed in their communities.
- Introduce Positive Exposure, which utilizes photography and video to transform perceptions of people living with genetic, physical, and behavioral differences.
- Discuss FRAME, a web-based educational library of genetic conditions that is changing the way healthcare students see people living with genetic differences.



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# Context: healthcare disparities

People with disabilities experience healthcare disparities:

- Screening and preventive services
- Access to care
- Health status and health outcomes
- Cancer diagnosis and treatment
- Satisfaction with care



# Context: health disparities

People with disabilities experience health disparities:

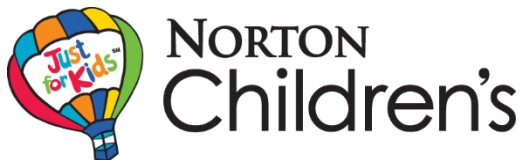
- Obesity
- Diabetes
- Cardiovascular disease
- Asthma
- Arthritis
- Mental health conditions: depression, anxiety



# Context: contributors to disparities

- Patient-level factors:
  - complex underlying health conditions and competing priorities
  - disadvantages in social determinants of health
- Systems-level factors:
  - inadequate training of healthcare professionals
  - ineffective communication accommodations
  - physical access barriers
  - inadequate knowledge among physicians about legal requirements to provide equitable care under the Americans with Disabilities Act (ADA) of 1990
  - **Erroneous assumptions about people with disability**
  - **Ableism attitudes among clinicians**
  - **? Physician bias**

Iezzoni LI, Rao SR, Resselam J, et al. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Aff (Millwood)*. 2021;40(2):297-306. doi:10.1377/hlthaff.2020.01452





## Implications of internalised ableism for the health and wellbeing of disabled young people

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**Funding information**  
Icelandic Centre for Research, Grant/Award Number: 174299-053

### Abstract

When conceptualising health and wellbeing among disabled people, the experience of internalised ableism must be considered. In this article, we argue that internalised ableism is indeed a health and wellbeing issue that materialises in numerous complex psychological, social and physical consequences. For theoretical grounding, we utilise critical disability studies, feminist theorising about solidarity and disability activists' concept of 'disability justice'. We draw on data from focus-group interviews with disabled young people, comprising ten men and eleven women, with different impairment types. The focus-group discussions revolve around various aspects of their wellbeing and participation in society, and possible and actual threats to the wellbeing of disabled children and young people in general. The analysis reflects various negative effects of internalised ableism on the identity, health and wellbeing of disabled young people. Family support, access to safer spaces and positive peer interactions are factors defining how internalised ableism develops, is maintained or defied. Peer support and solidarity are strong indicators of

- **Ableism** is the discrimination and oppression of disabled people; the societal belief that being able-bodied is “normal” and is preferred.
- A result of bias against people with disabilities.

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*Social Health Illn.* 2022;00:1–17.

wileyonlinelibrary.com/journal/shil | 1



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MEDICINE



microaggressions/macroaggressions



internalization of ableism/oppresion



mental health concerns: anxiety, depression, isolation,  
feelings of inferiority, powerlessness, negative body image





# Internalization of ableism

- ...if you are born disabled, your parents need education on everything their child can do. Instead the doctor comes and says, “This is what is wrong, and this ... and this... and this.” When rather someone should come and say, “These are the resources available for you .... Your child can do this ... and this ... and this.” The focus is too often on what is wrong with the baby but not what the baby is capable of.
- There are often too little expectations towards disabled children. You know, many parents really have to fight in order to have the same expectations aimed at their disabled child as any other child.



# Internalization of ableism

**Ása:** There is a connection between depression and anxiety and for example, disability. And you know, it is most likely because society has a negative view of disability.

**Sólrún:** I think that society could be more positive. “Yes, okay, you are like this!”

**Researcher:** Can I ask you, Ása, when you say the connection between depression, anxiety and disability is because of society, can you name an example?

**Ása:** It’s because of prejudice towards disability. People with disabilities do not think they are acceptable to others, and then they isolate themselves and become anxious.

**Sólrún:** I became depressed because of my disability, but also because of prejudice from others.



# Bias

- Preconceived attitude or belief, conscious or unconscious, regarding a group of people that influences how we perceive, interact, and behave toward the group.
- Studies of racial/ethnic bias among physicians have found that unconscious and conscious beliefs significantly effect treatment decisions, patient outcomes, and other aspects of care.
- If parallel effects hold true for people with disability, physician bias toward disability likely contributes to known healthcare disparities in this population.

By Lisa I. Iezzoni, Sowmya R. Rao, Julie Ressler, Dragana Bolcic-Jankovic, Nicole D. Agaronnik, Karen Donelan, Tara Lagu, and Eric G. Campbell

# Physicians' Perceptions Of People With Disability And Their Health Care

DOI: 10.1377/hlthaff.2020.01452  
HEALTH AFFAIRS 40,  
NO. 2 (2021): 297-306  
©2021 Project HOPE—  
The People-to-People Health  
Foundation, Inc.

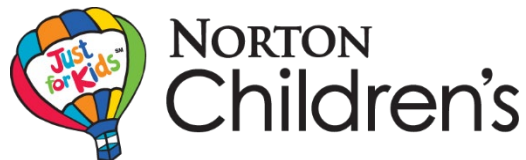
**ABSTRACT** More than sixty-one million Americans have disabilities, and increasing evidence documents that they experience health care disparities. Although many factors likely contribute to these disparities, one little-studied but potential cause involves physicians' perceptions of people with disability. In our survey of 714 practicing US physicians nationwide, 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. Only 40.7 percent of physicians were very confident about their ability to provide the same quality of care to patients with disability, just 56.5 percent strongly agreed that they welcomed patients with disability into their practices, and 18.1 percent strongly agreed that the health care system often treats these patients unfairly. More than thirty years after the Americans with Disabilities Act of 1990 was enacted, these findings about physicians' perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could contribute to persistent health care disparities affecting people with disability.

**Lisa I. Iezzoni** (liezzoni@mgh.harvard.edu) is a professor of medicine at Harvard Medical School, based at the Health Policy Research Center, Mongan Institute, Massachusetts General Hospital, in Boston, Massachusetts.

**Sowmya R. Rao** is a statistician in the Biostatistics Center at Massachusetts General Hospital and at the Boston University School of Public Health.

**Julie Ressler** is a senior research coordinator in the Center for Bioethics and Humanities, Anschutz Medical Campus, University of Colorado, in Aurora, Colorado.

**Dragana Bolcic-Jankovic** is the director of survey operations and a research fellow in the Center for Survey Research at

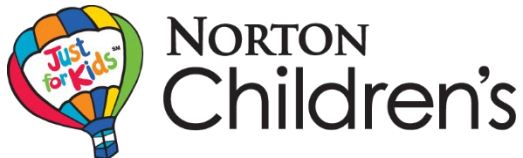




# Perceptions of Disability - Physicians

- 82% of physicians report that people with significant disability have overall worse quality of life than other people
- 41% of physicians are very confident in their ability to provide equal quality care to people with disability
- 56% strongly welcome people with disability into their practices
  - Women physicians more welcoming
  - Younger more welcoming
  - Physicians confident about their ability to provide care to disabled people more welcoming
  - University setting more welcoming than private practice

lezzoni LI, Rao SR, Ressalam J, et al. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Aff (Millwood)*. 2021;40(2):297-306. doi:10.1377/hlthaff.2020.01452





# Perceptions of Disability - Patients

**1994-1995 National Health Interview Survey-Disability self-respondents “Perceives self as NOT having a disability.”**

58% of blind, very low vision

73% of deaf, very hard of hearing

32% of walker users

20% of manual wheelchair users

16% of power wheelchair users

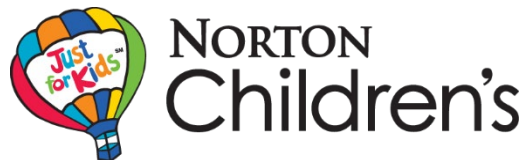
[https://www.cdc.gov/nchs/nhis/nhis\\_disability.htm](https://www.cdc.gov/nchs/nhis/nhis_disability.htm)



# The Disability Paradox

- Many people with serious and persistent disabilities report that they experience a good or excellent quality of life, even when to most external observers these people seem to live a less desirable daily existence.
- **Quality of life:** an individual's perception of their well-being and general satisfaction with life (personal perspective)
- Subjective life satisfaction of disabled people is usually comparable to that of non-disabled people.
  - People with different expectations will report that they have a different quality of life even when they have the same clinical condition
- Many people with disabilities, particularly if their conditions are congenital or long-term, do not necessarily perceive their disability as a problem or pathology.

Albrecht GL, Devlieger PJ. The disability paradox: high quality of life against all odds. Social Science and Medicine. 1999 (48)977-88.





*Given potential bias of physicians, how do we ensure that people with disability get equal quality care?*

Raises questions about care for people with disability in times of scarce resources (COVID-19 pandemic).

- Crisis Standards of Care (CSC)
- **3/31/2020 Office for Civil Rights at the U.S. Department of Health and Human Services**, “in this time of emergency, the laudable goal of providing care quickly and efficiently must be guided by the fundamental principles of fairness, equality, and compassion that animate our civil rights laws. This is particularly true with respect to the treatment of persons with disabilities during medical emergencies as they possess the same dignity and worth as everyone else.”
- States changed CSC





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*Why should people with disability need to prove to their doctor that they value the quality of their life to get equal quality of care?*

# Causes and ways to help

- Ableist attitudes dominate medicine – training focus on medical model (pathology)
  - Functional model (environmental context)
- In our culture we are implicitly bound to think of able-bodied people when we think of a good quality of life
  - Biases come from our culture, but what we teach ourselves, what we choose to associate, is up to us
- Lack of exposure of learners to disabled people, in medical school and often throughout life
  - All levels of medical training should include more training about disability
  - Make medical school education more accessible to disabled people
  - Use disability self-advocates in medical training
  - **Change training to provide greater empathy and understanding about patients' daily lives-**  
**Rick Guidotti, Positive Exposure**



Corrie Harris, MD  
Corrie.Harris@Louisville.edu



NORTON  
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MEDICINE



POSITIVE  
EXPOSURE









SAINT LAURENT  
PARIS

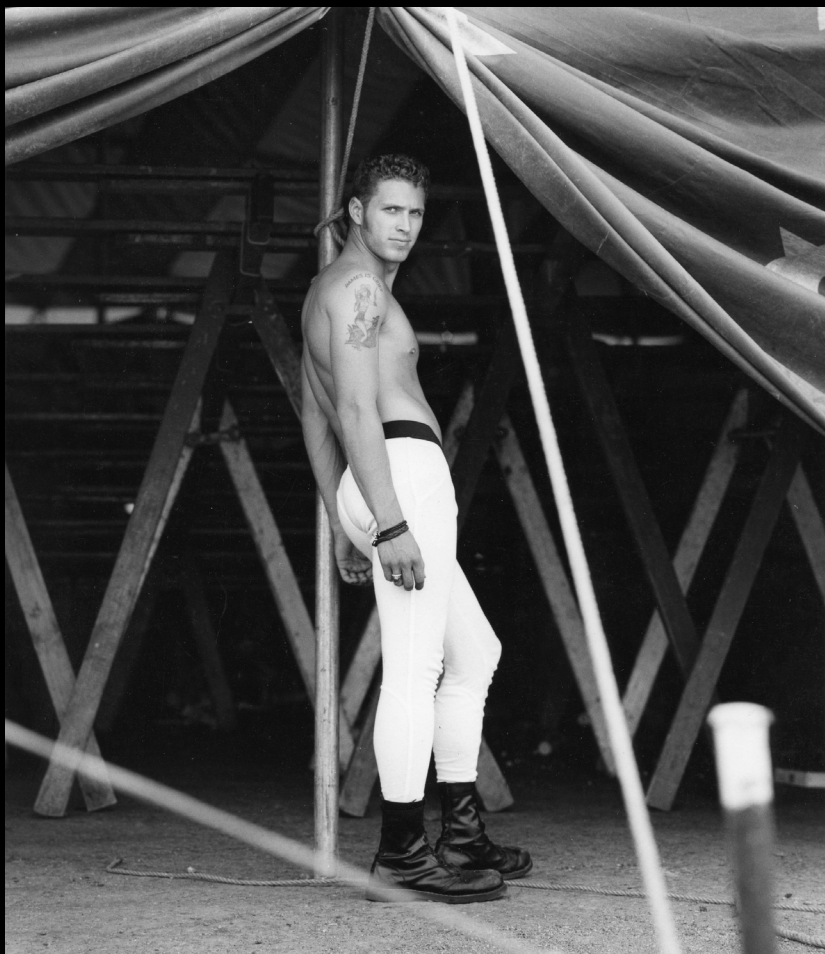




1. Du **satin** effet nylon pour duo de saison

À gauche. Manteau façon doudoune en satin matelassé, coupe cintrée (Atsuro Tayama/Kashiyama), robe de satin noir attachée en licou (Calvin Klein). Bottes cuissardes (Robert Clergerie).  
 À droite. Manteau de simili-fourrure à motifs léopard, épaules étroites et coupe près du corps (DKNY), robe sans manches, en tricot de laine noire (DKNY).

flash  
 sur **4** matières...



À gauche. Veste ligne princesse, col tailleur arrondi, sur pantalon cigarette ultra-court (Hélène Barbeau, 210 \$ et 150 \$).

Chaussures rouges (Anne Klein).

À droite. Veste tout coton vert pomme à rayures rouges, simple boutonnage, et pantalon cigarette à revers (More Dash Than Cash, 240 \$ et 165 \$); pull cache-cœur rouge en coton et polyamide, lacé devant (Sisley, 99 \$).

et se porte surtout sur pantalon cigarette...

Dessous, tout au plus, un licou ou un bandeau.





ALBINISM







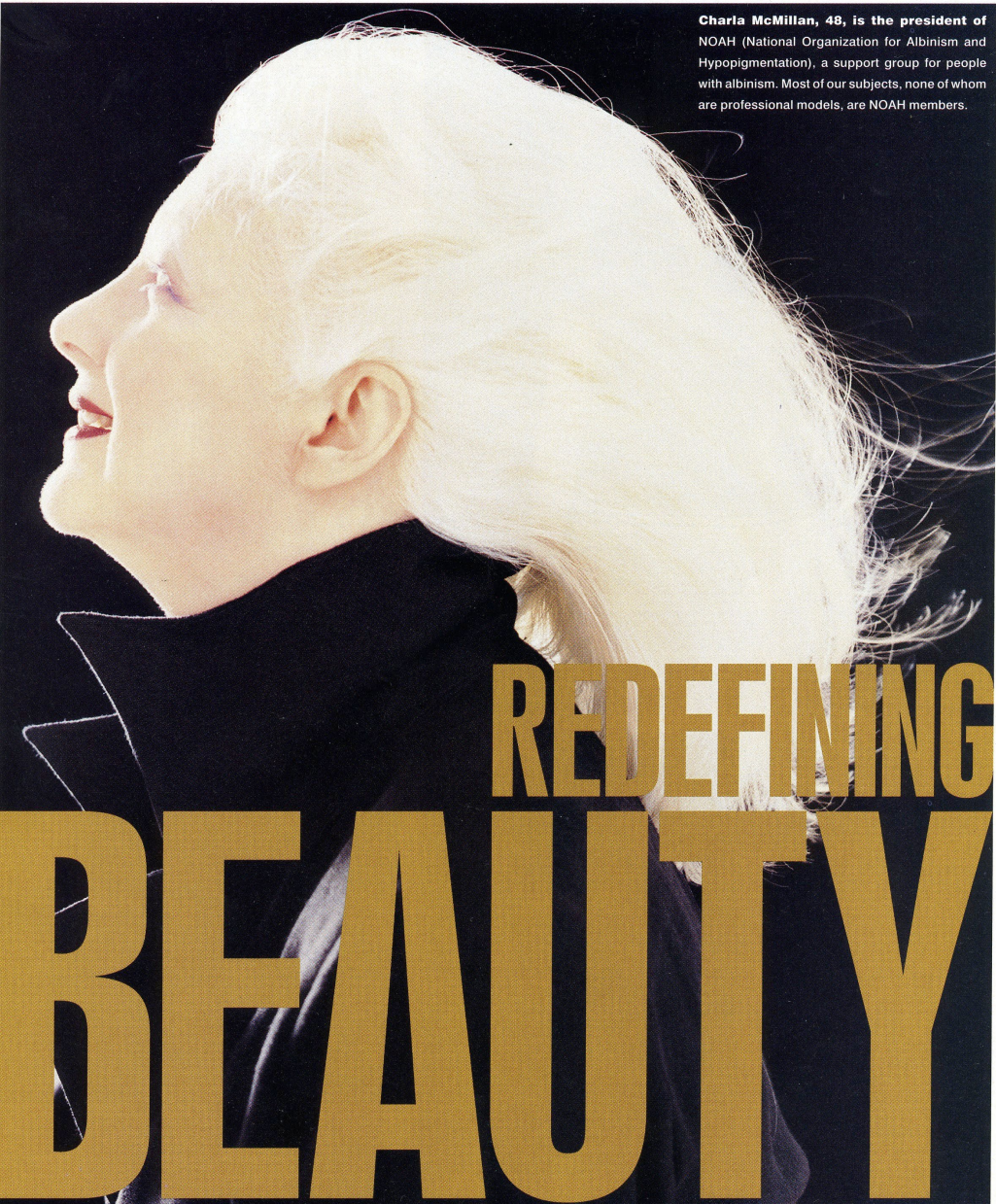




CHANGE  
HOW YOU  
SEE, SEE  
HOW YOU  
CHANGE

---

POSITIVE  
EXPOSURE



Charla McMillan, 48, is the president of NOAH (National Organization for Albinism and Hypopigmentation), a support group for people with albinism. Most of our subjects, none of whom are professional models, are NOAH members.

# REDEFINING BEAUTY

EYEWITNESS PHOTOGRAPHER RICK GUIDOTTI OPENS OUR EYES TO THE BEAUTY OF ALBINISM. 65 LIFE













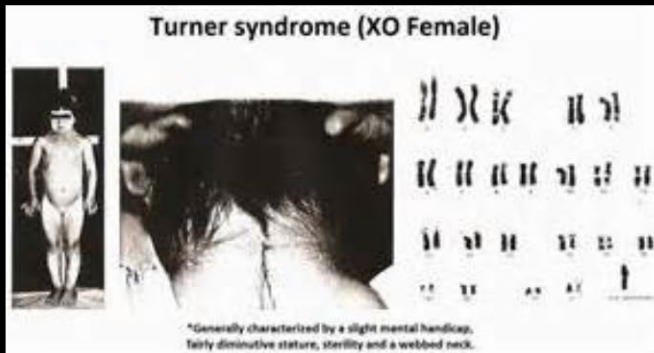


**Genetic Alliance**



The Chromosome 18  
Registry & Research Society

### Turner syndrome (XO Female)

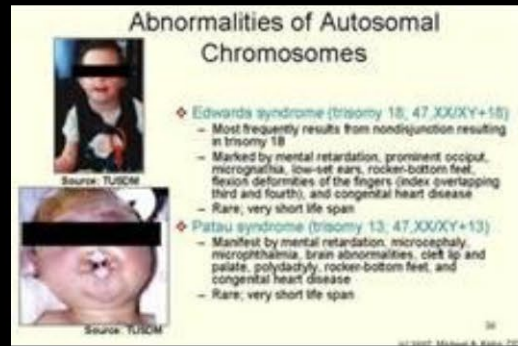


Turner syndrome (XO Female) is characterized by a karyotype showing a missing X chromosome. Clinical features include a webbed neck, short stature, and a slightly webbed neck. The image shows a female patient with a webbed neck, a close-up of the neck, and a karyotype with a missing X chromosome.

\*Generally characterized by a slight mental handicap, fairly diminutive stature, sterility and a webbed neck.



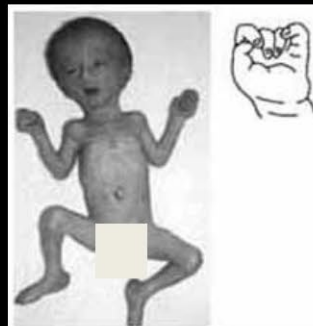
### Abnormalities of Autosomal Chromosomes



Abnormalities of Autosomal Chromosomes

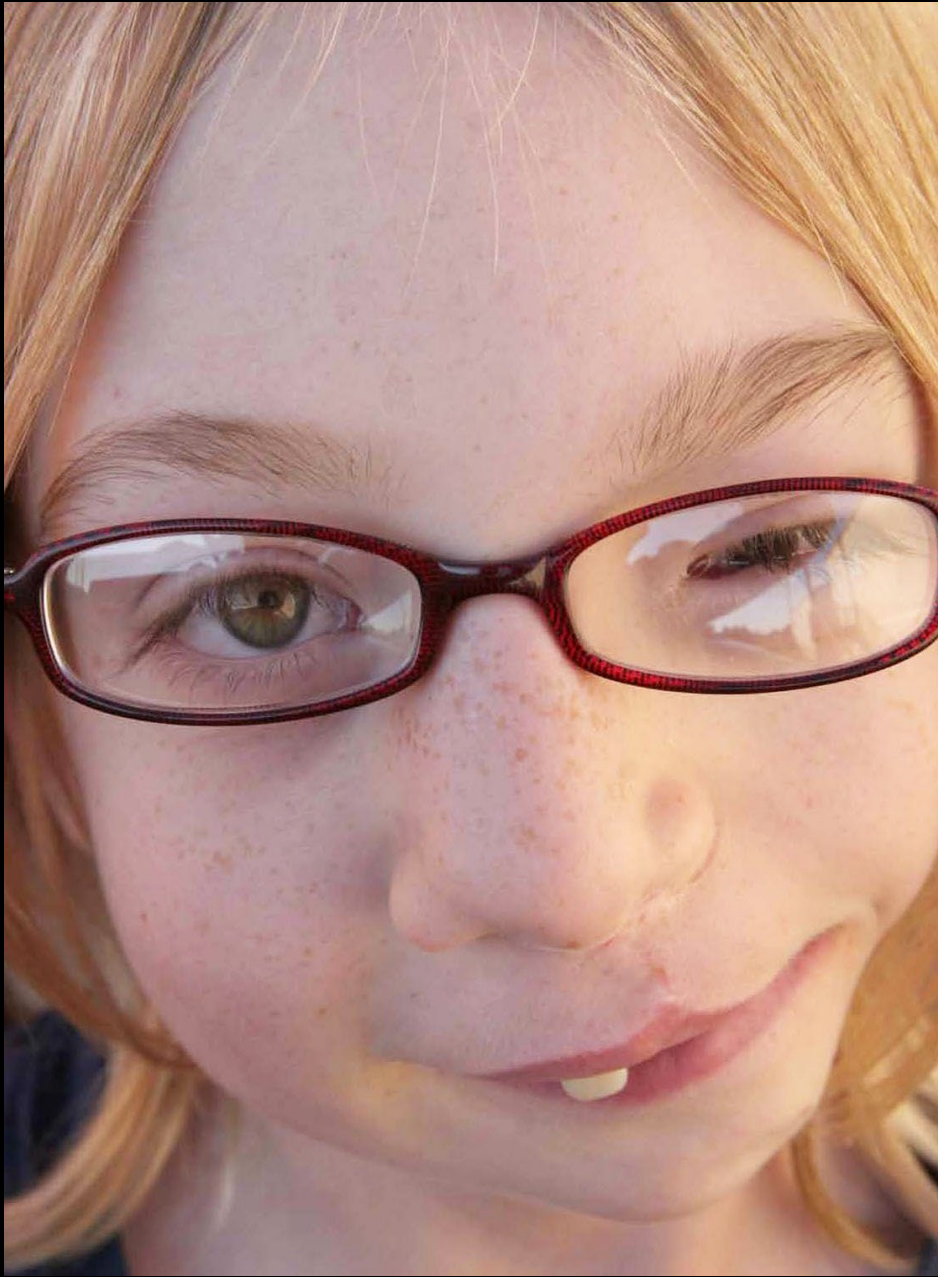
- ♦ Edwards syndrome (trisomy 18; 47,XXXYY+18)
  - Most frequently results from nondisjunction resulting in Trisomy 18
  - Marked by mental retardation, prominent occiput, micrognathia, low-set ears, rocker-bottom feet, flexion deformities of the fingers (index overlapping third and fourth), and congenital heart disease
  - Rare; very short life span
- ♦ Patau syndrome (trisomy 13; 47,XXXYY+13)
  - Manifest by mental retardation, microcephaly, microphthalmia, brain abnormalities, cleft lip and palate, polydactyly, rocker-bottom feet, and congenital heart disease
  - Rare; very short life span

Source: TUSCM



### Chromosome Anomalies















[genome.gov](http://genome.gov)

National Human Genome Research Institute

National Institutes of Health



MARFAN Syndrome





Billy





Caleb living with Achondroplasia



Dr. Nadia

Maggie and  
Danielle at the  
Costello  
Syndrome  
Conference







Jahzara living with Goldenhar syndrome

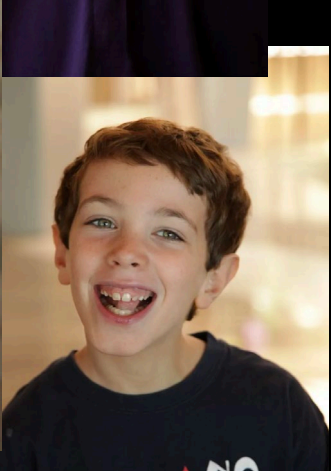
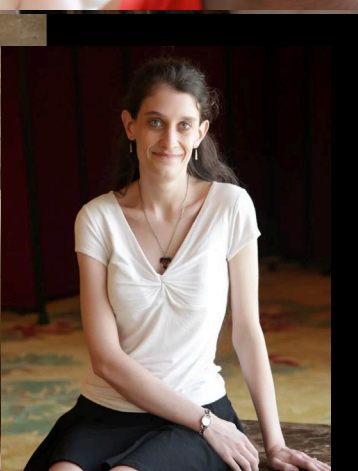
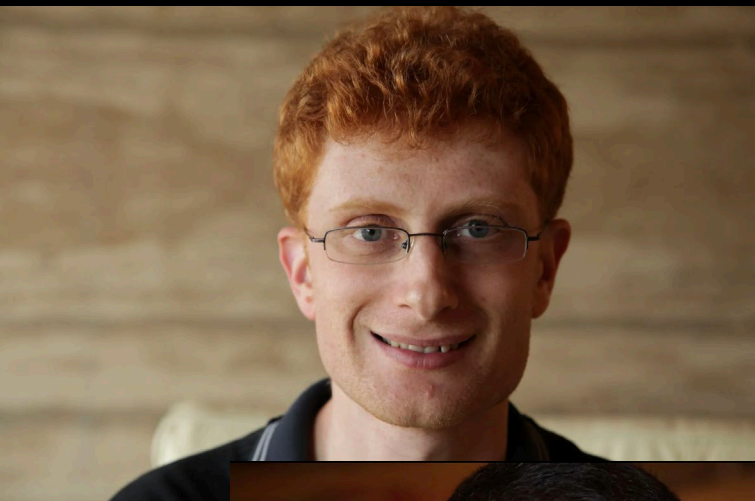


Jayda  
living with  
22q11.2  
deletion



Lukas living  
with  
Fragile X syndrome





Simone  
living with  
Down  
syndrome





Ronan living with Prader-Willi syndrome

Curtis and Alex  
living with  
Vitiligo





Jasper living with Angelman syndrome



SPINAL MUSCULAR ATROPHY Family Conference







Khloee



The Amazing Judith Heumann

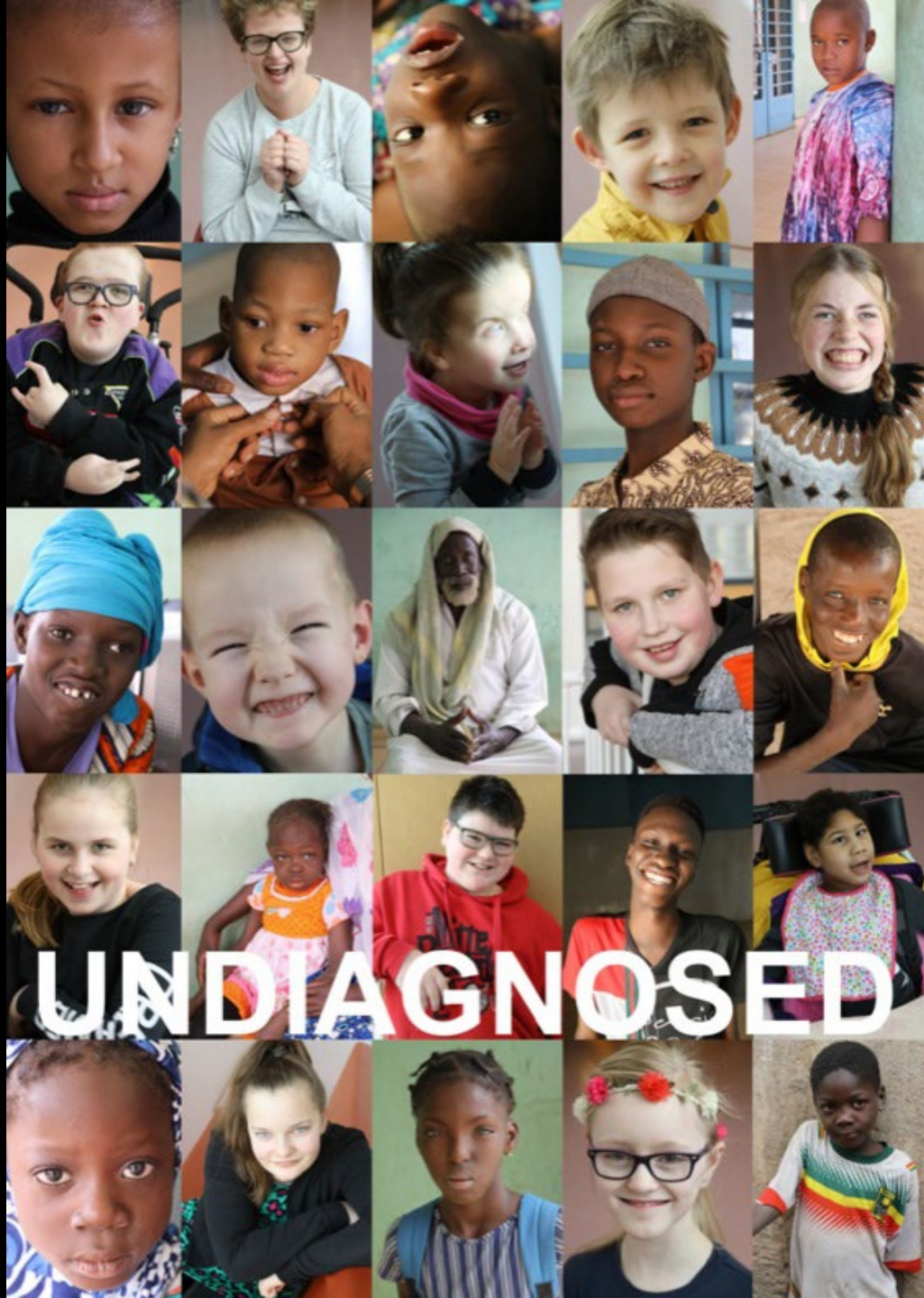


Gaten living with living with Cleidocranial Dysplasia



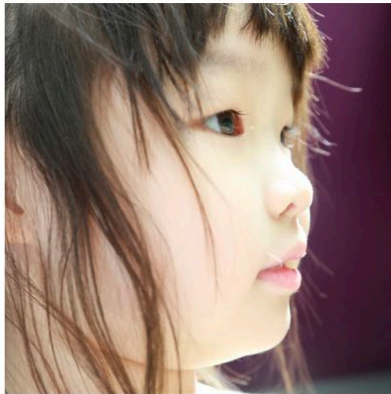
# THE UNDIAGNOSED

RICK GUIDOTTI POSITIVE EXPOSURE  
WILHELM FOUNDATION

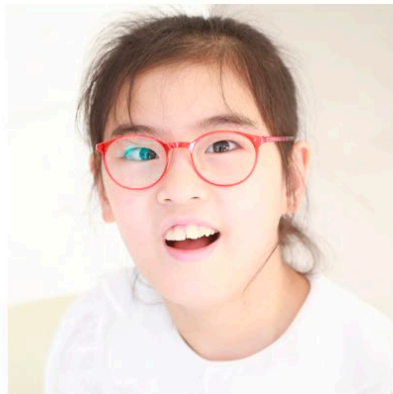
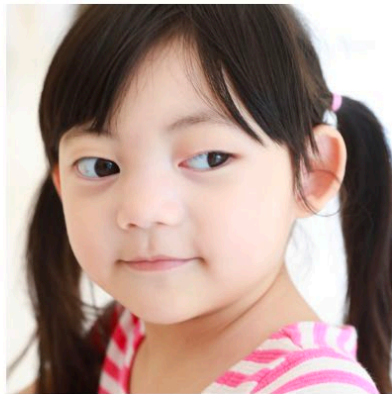
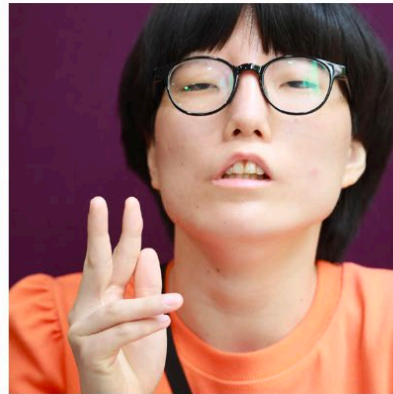


UNDIAGNOSED

함께하는 소중한 추억



희귀질환  
포  토  
프로젝트





Kaelin living with living with Sturge-Weber syndrome



**Self - Acceptance**



**Self - Esteem**

**=**

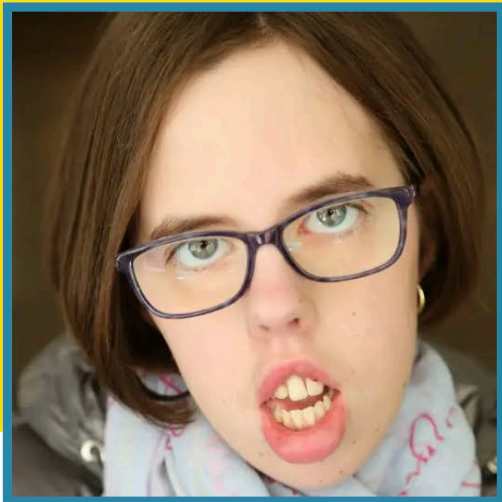
**Self - Advocacy**



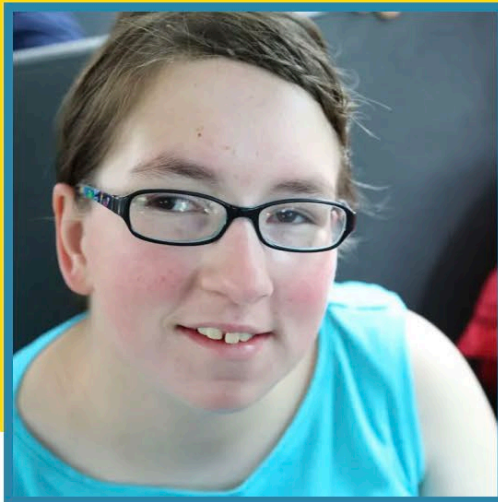
POSITIVE  
EXPOSURE

# PEARLS Project

## Featured Ambassadors



Grace



Rebecca



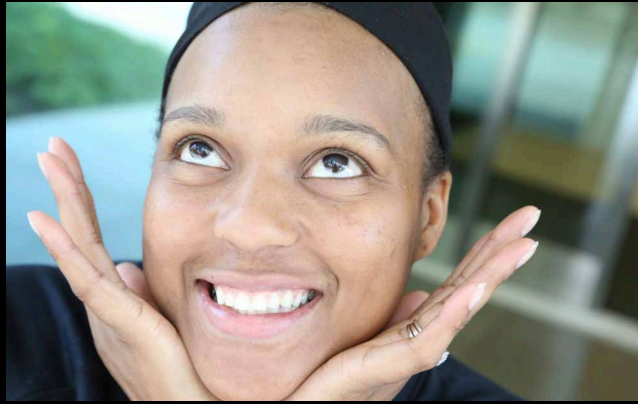
Talia

PJ living with  
Arthrogryposis  
Multiplex  
Congenita



# FRAME

FACES REDEFINING THE ART OF MEDICAL EDUCATION





**REPRESENTATION OF PATIENTS**

**EPISODE 1: DERMATOLOGY**



# [ REPRESENTATION OF PATIENTS ]

EPISODE 2: AGING







A



B



C



D



Familial Marfan Syndrome | Consultant360



A



B

Sturge-Weber Syndrome: A Review - ScienceDirect

[Visit](#)

*textbook* **BEAUTY**

**POSITIVE  
EXPOSURE**



# Amir

*textbook* **BEAUTY**

SYNDROME

**ANGELMAN'S SYNDROME**

POSITIVE  
EXPOSURE

[Open Gallery](#)



**Lily**

**Chromosome 4p-  
TEXTBOOK BEAUTY**

A close-up portrait of a young woman with brown hair and glasses, smiling. She has a prominent, reddish-purple, textured lesion on her forehead and cheek, characteristic of Sturge Weber Syndrome. The background is a plain, light-colored wall.

# Kaelin

**TEXTBOOK BEAUTY: STURGE WEBER SYNDROME**

POSITIVE EXPOSURE

[Open Gallery](#)

**POSITIVE109**  
**EXPOSURE**

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@Museum Mile 14 East 109th St, NY











# כולנו דומים. כולנו מיוחדים.

בית איזו שפירא  
משיקו באיכות וחינוך של אנשים עם מוגבלויות  
במסגרת יוזמת "אנשים שונים"

ארועי שנת ה-35  
4-21/7/2015



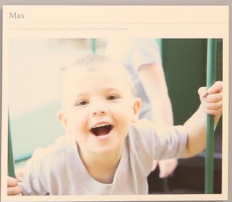
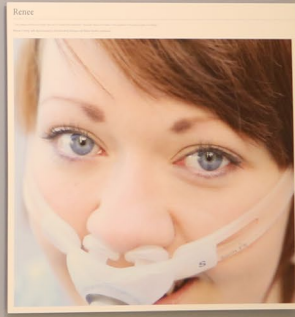
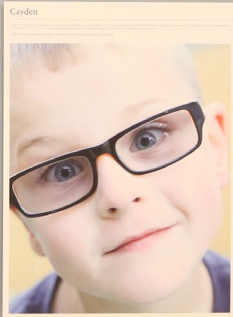
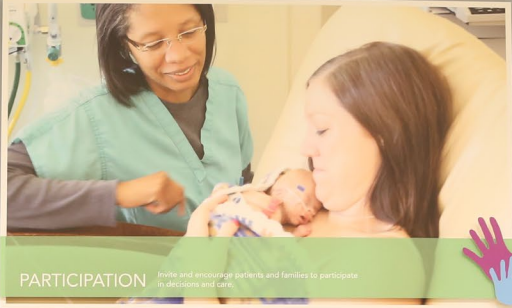
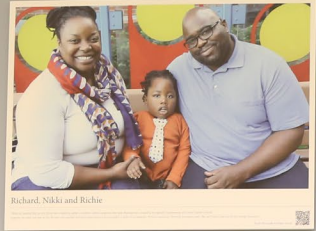
• סרטים בסינמטק • תערוכת צילומים

• מפגשי ברים • כנס בינלאומי









**POSITIVE  
EXPOSURE**

The spirit of  
difference

**CHANGE HOW YOU SEE,  
SEE HOW YOU CHANGE.**

Presented by The Resource Exchange



**POSITIVE EXPOSURE: THE SPIRIT OF DIFFERENCE**  
PRESENTED BY THE RESOURCE EXCHANGE



**TRE**

The Resource Exchange

Gallery Hours  
Monday-Saturday, 10am - 7pm  
Sunday, 11am - 6pm



THE SPIRIT OF DIFFERENCE  
GUIDE



**POSITIVE  
EXPOSURE**  
THE SPIRIT OF DIFFERENCE  
GUIDE









# POSITIVE EXPOSURE

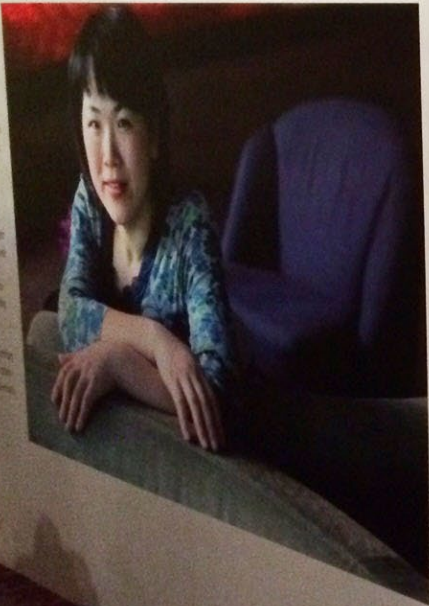
The spirit of difference

## CHANGE HOW YOU SEE, SEE HOW YOU CHANGE.





「I am one with my skin」



「I am one with my skin」

**Eugene**

Senior Manager



Scott's Emulsion is a natural source of Vitamin D3 and Vitamin A, which are essential for skin health. It is also a rich source of Omega-3 fatty acids, which help to reduce inflammation and improve skin texture. Scott's Emulsion is a natural source of Vitamin D3 and Vitamin A, which are essential for skin health. It is also a rich source of Omega-3 fatty acids, which help to reduce inflammation and improve skin texture.

Scott's Emulsion



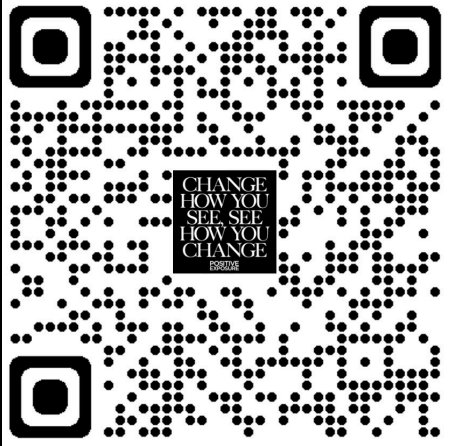
POSITIVEEXPOSURE.ORG

CHANGE  
HOW YOU  
SEE, SEE  
HOW YOU  
CHANGE

POSITIVE  
EXPOSURE



PositiveExposure



Q & A

THANK YOU!

**South Carolina Chapter**

INCORPORATED IN SOUTH CAROLINA

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



2024 SCAAP CATCH MEETING

# Thank you for joining us!

*We hope to see you all next year...*

**South Carolina Chapter**

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American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN™



2024 SCAAP CATCH MEETING