Using Narrative Medicine to Explore Responses to the Positive Exposure Photography Exhibition at DHMC

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Dartmouth
GEISEL SCHOOL OF
MEDICINE

Acknowledgements

Thank you

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    - Geisel Ethics and Human Values Program
- Marianne Barthel
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- Geisel School of Medicine’s Office of Medical Education
- Ethics Institute at Dartmouth
- The Gertrude H. Mertens Arts Fund at Dartmouth-Hitchcock

- Participants in the narrative medicine sessions

Positive Exposure

- Nonprofit organization that uses photography to help fight stigma and create more inclusive communities
- Started by fashion photographer Rick Guidotti

CHANGE
HOW YOU
SEE, SEE
HOW YOU
CHANGE

I AM A WOMAN.
I HAVE FEELINGS.
I AM NOT DEAF.
I DO NOT HAVE
RED EYES,
AND I CANNOT
TELL THE FUTURE.

WE DID NOT
GET THIS WAY BY BEING
STRUCK BY LIGHTNING,
AND WE
DON'T HAVE
MAGICAL
POWERS.

I HAVE OFTEN FELT LIKE A PROJECTION SCREEN—A WHITE WINDOW UPON WHICH PEOPLE CAST THEIR OWN DESIGNS.

DAMN STRAIGHT!

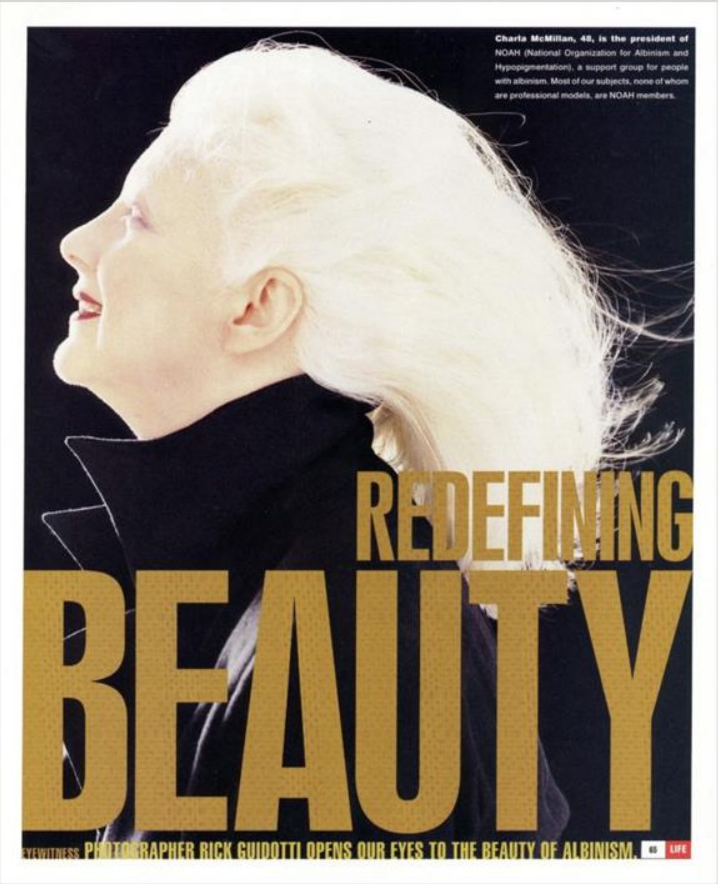
I'VE REMAINED TRUE
TO MYSELF. IT'S MY
ONLY OPTION.

TO INSULT ME

STRIPPED
OF MY
PERSONHOOD.

AT SOME POINT, FOR EACH OF US,
THERE COMES A TIME OF
TRUE AND
TOTAL ACCEPTANCE.

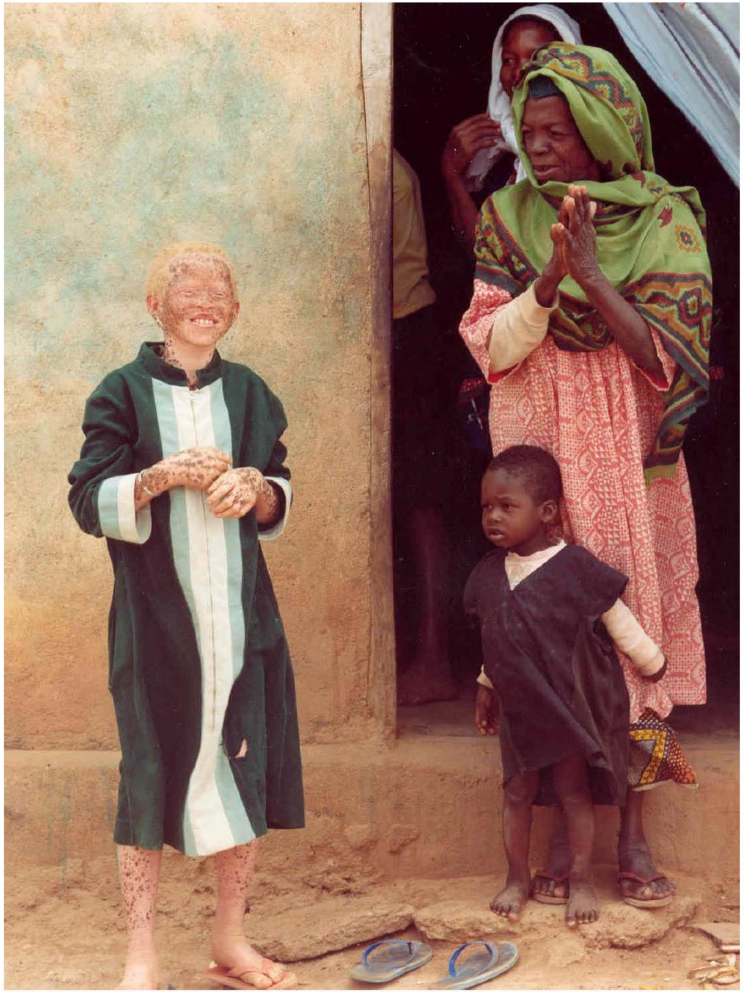
This first series of images appeared in LIFE Magazine in a cover story entitled "Redefining Beauty" in 1998. The 5-page photographic essay launched Positive Exposure and identified people living with albinism, their families and local support organizations around the world.



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



SIRI, MALI

Siri is a student and lives with her family in Bamako, Mali. She and her family are powerful advocates for people living with albinism in West Africa.

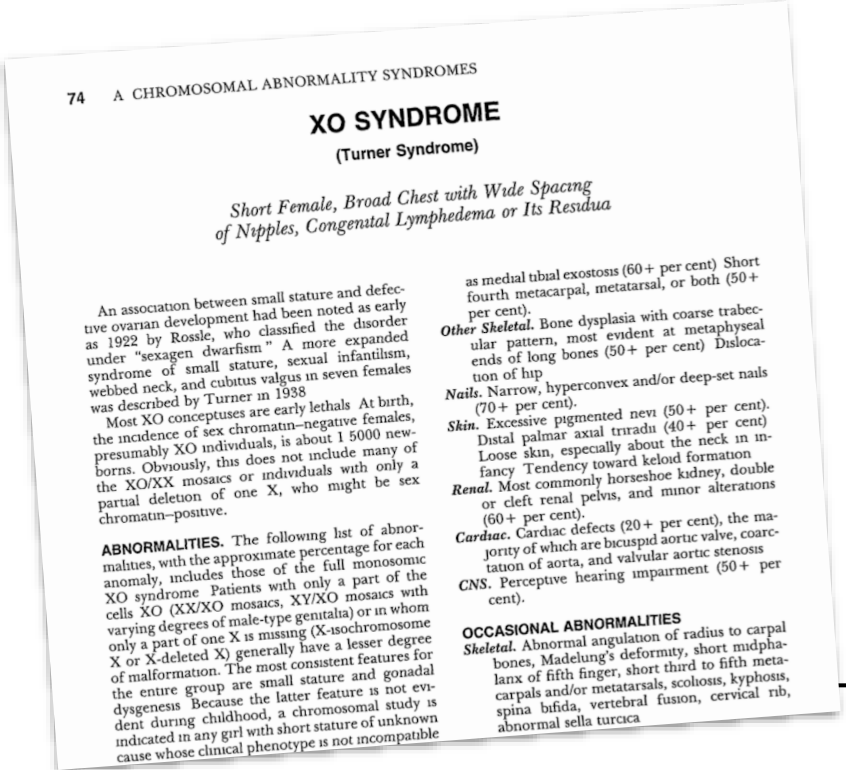
ALBINISM
albinism.org

Positive Exposure

Positive Exposure at DHMC

- Exhibition
- Interdisciplinary Grand Rounds talk
- Narrative Medicine component

Presentation of Genetic Differences in Medical Education - Turner Syndrome



74 A CHROMOSOMAL ABNORMALITY SYNDROMES

XO SYNDROME

(Turner Syndrome)

Short Female, Broad Chest with Wide Spacing of Nipples, Congenital Lymphedema or Its Residua

An association between small stature and defective ovarian development had been noted as early as 1922 by Rossle, who classified the disorder under "sexagen dwarfism" A more expanded syndrome of small stature, sexual infantilism, webbed neck, and cubitus valgus in seven females was described by Turner in 1938

Most XO conceptuses are early lethals At birth, the incidence of sex chromatin–negative females, presumably XO individuals, is about 1 5000 newborns. Obviously, this does not include many of the XO/XX mosaics or individuals with only a partial deletion of one X, who might be sex chromatin–positive.

ABNORMALITIES. The following list of abnormalities, with the approximate percentage for each anomaly, includes those of the full monosomic XO syndrome Patients with only a part of the cells XO (XX/XO mosaics, XY/XO mosaics with varying degrees of male-type genitalia) or in whom only a part of one X is missing (X-isochromosome X or X-deleted X) generally have a lesser degree of malformation. The most consistent features for the entire group are small stature and gonadal dysgenesis Because the latter feature is not evident during childhood, a chromosomal study is indicated in any girl with short stature of unknown cause whose clinical phenotype is not incompatible

as medial tibial exostosis (60+ per cent) Short fourth metacarpal, metatarsal, or both (50+ per cent).

Other Skeletal. Bone dysplasia with coarse trabecular pattern, most evident at metaphyseal ends of long bones (50+ per cent) Dislocation of hip

Nails. Narrow, hyperconvex and/or deep-set nails (70+ per cent).

Skin. Excessive pigmented nevi (50+ per cent). Distal palmar axial triradii (40+ per cent) Loose skin, especially about the neck in infancy Tendency toward keloid formation

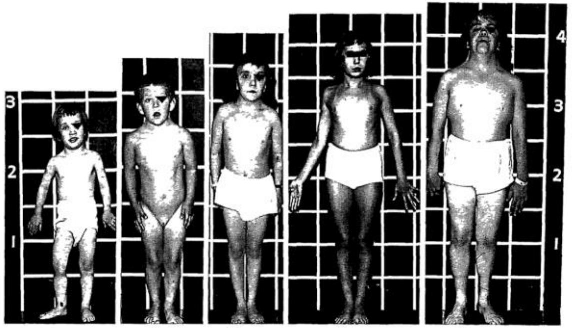
Renal. Most commonly horseshoe kidney, double or cleft renal pelvis, and minor alterations (60+ per cent).

Cardiac. Cardiac defects (20+ per cent), the majority of which are bicuspid aortic valve, coarctation of aorta, and valvular aortic stenosis

CNS. Perceptive hearing impairment (50+ per cent).

OCCASIONAL ABNORMALITIES

Skeletal. Abnormal angulation of radius to carpal bones, Madelung's deformity, short midphalanx of fifth finger, short third to fifth metacarpals and/or metatarsals, scoliosis, kyphosis, spina bifida, vertebral fusion, cervical rib, abnormal sella turcica



3 years | 4 years 6 months | 10 years 5 months | 12 years | 14 years 10 months

Five girls with the XO syndrome Note the variability of such features as webbed neck and broad chest

Ten day old XO patient who still has lymph-filled bilateral cysts in the posterior neck area, the cause for the webbed neck and for the prominent ears This patient had abdominal muscle hypoplasia with bulging flanks, possibly secondary to earlier undue distention of the abdomen by fluid Thus, this baby survived fetal life and was born with a more severe degree of lymphedema than usual

Jones KL, ed. *Smith's Recognizable Patterns of Human Malformation*, 4th ed., 1988

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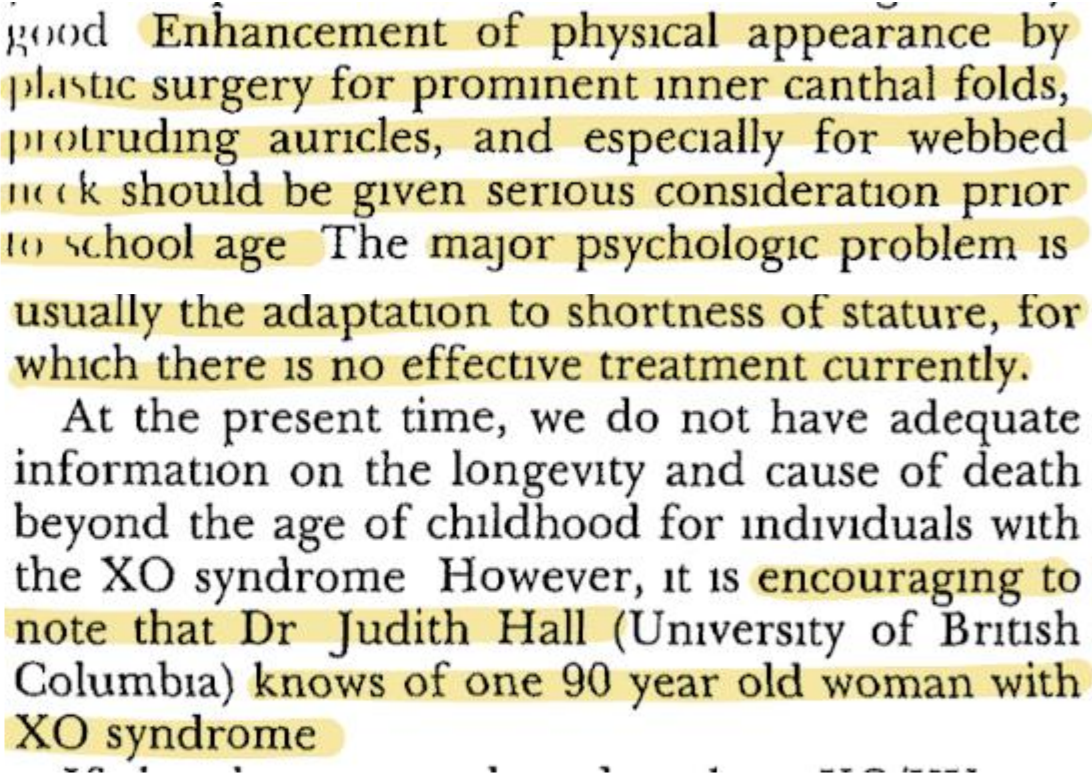
XO SYNDROME

(Turner Syndrome)

XO syndrome *A* to *C*, One month old Note lymphedema, prominent ears, and loose folds of skin in posterior neck with low hair line *D*, Same girl at two years and at four years, with height ages of 17 months and three years, respectively *E*, Low posterior hair line and residual lateral neck web *F*, Narrow, hyperconvex, deep-set fingernails, residual puffiness (*A* to *C*, *E*, and *F* from Lemli, L , and Smith, D W J Pediatr , *63* 577, 1963)



good Enhancement of physical appearance by plastic surgery for prominent inner canthal folds, protruding auricles, and especially for webbed neck should be given serious consideration prior to school age The major psychologic problem is usually the adaptation to shortness of stature, for which there is no effective treatment currently.

At the present time, we do not have adequate information on the longevity and cause of death beyond the age of childhood for individuals with the XO syndrome However, it is encouraging to note that Dr Judith Hall (University of British Columbia) knows of one 90 year old woman with XO syndrome

Jones KL, ed. *Smith's Recognizable Patterns of Human Malformation*, 4th ed., 1988

[redacted]

Geisel School of Medicine at Dartmouth lecture notes

AUBREE

Aubree is 9 years old.
Her short stature doesn't bother her at all.

TURNER SYNDROME
turnersyndrome.org

Positive Exposure

IRINA

Irina was born in Russia. She has two younger sisters. She likes Spiderman, Batman, pirates and trucks. She also likes to ride her bike and play basketball.

ACHONDROPLASIA
lpaonline.org

Positive Exposure

BILLY

Billy wants people living with this condition to be proud of their long fingers, arms, legs and scoliosis.

MARFAN SYNDROME
marfan.org

Positive Exposure

Narrative Medicine

Hannah

Hannah loves gymnastics and her favorite colors are pink and blue. She and her sister, Bari, love swimming and have a dog named Amigo. Hannah, her sister and dad are living with Treacher Collins Syndrome.

TREACHER COLLINS SYNDROME

myface.org

Positive Exposure

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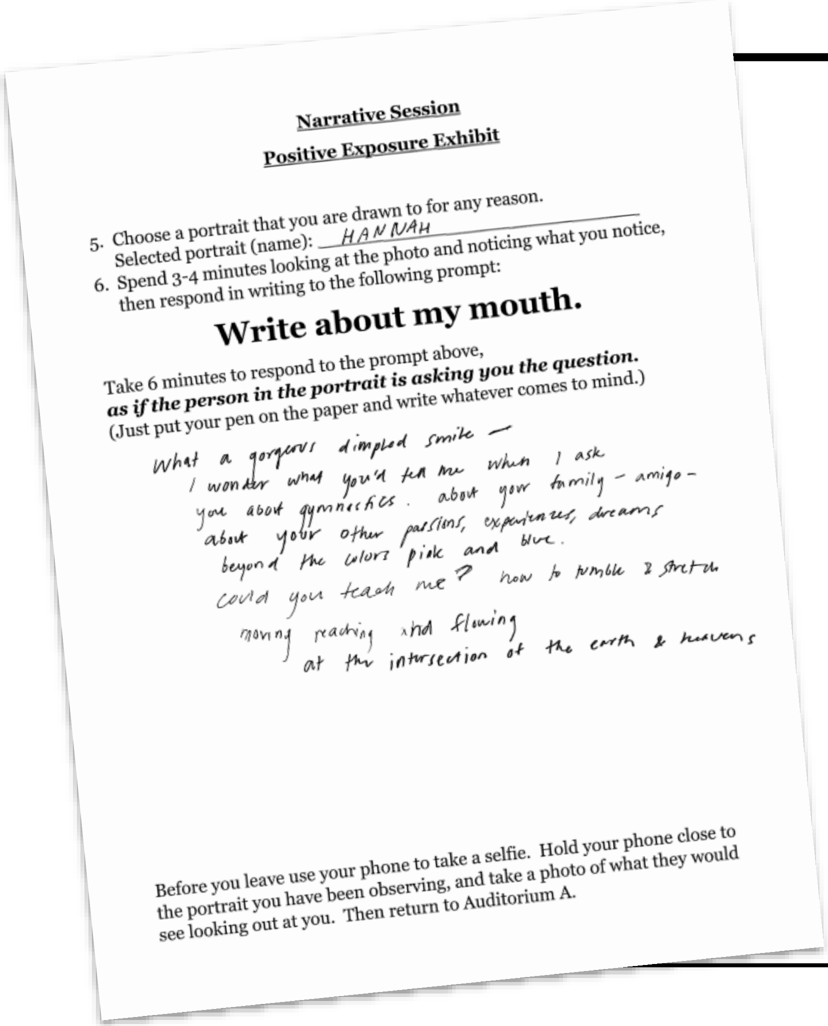


Narrative Session

Positive Exposure Exhibit

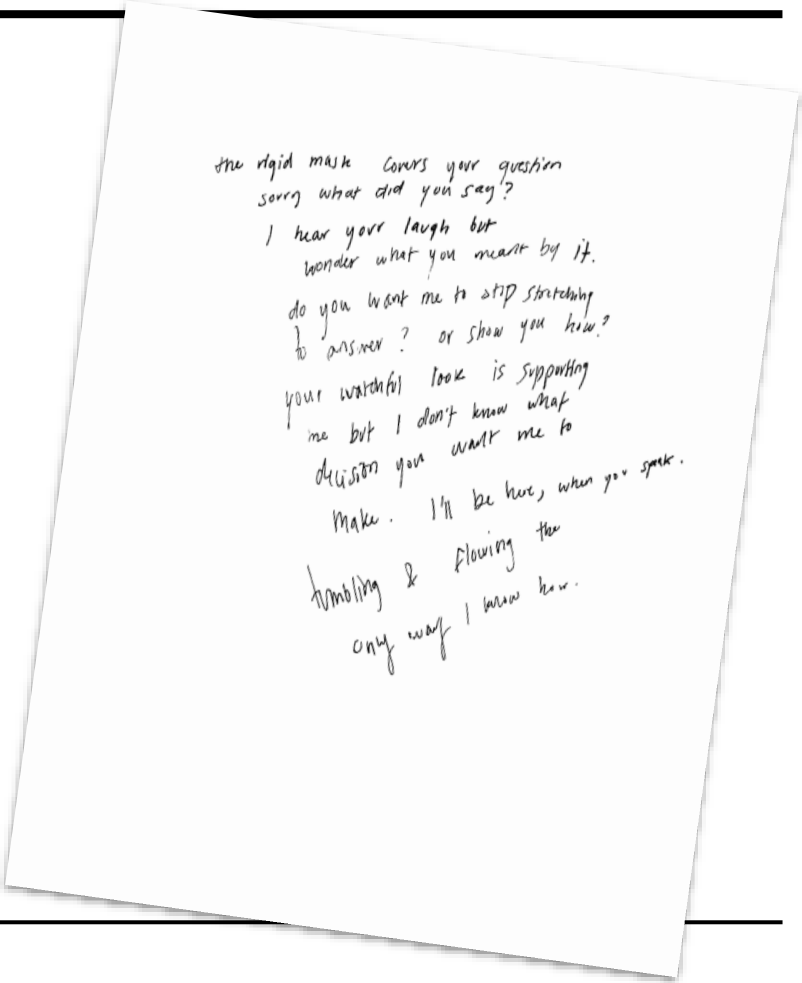
5. Choose a portrait that you are drawn to for any reason.
Selected portrait (name): HANNAH
6. Spend 3-4 minutes looking at the photo and noticing what you notice, then respond in writing to the following prompt:

Write about my mouth.

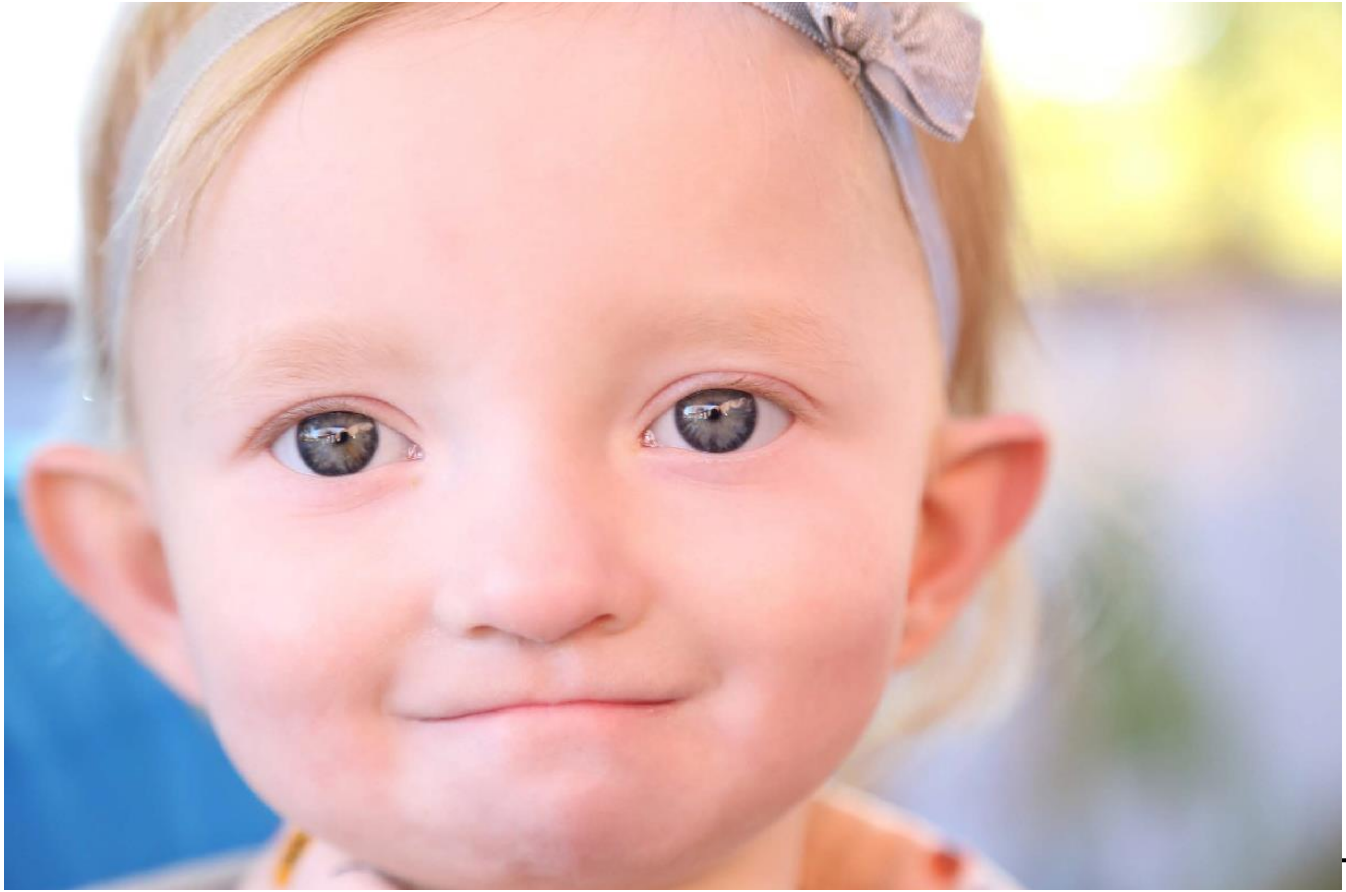
Take 6 minutes to respond to the prompt above, ***as if the person in the portrait is asking you the question.*** (Just put your pen on the paper and write whatever comes to mind.)

What a gorgeous dimpled smile —
I wonder what you'd tell me when I ask
you about gymnastics. about your family – amigo –
about your other passions, experiences, dreams
beyond the colors pink and blue.
could you teach me? how to tumble & stretch
moving reaching and flowing
at the intersection of the earth & heavens

Before you leave use your phone to take a selfie. Hold your phone close to the portrait you have been observing, and take a photo of what they would see looking out at you. Then return to Auditorium A.



the rigid mask covers your question
sorry what did you say?
I hear your laugh but
wonder what you meant by it.
do you want me to stop stretching
to answer? or show you how?
your watchful look is supporting
me but I don't know what
decision you want me to
make. I'll be here, when you speak.
tumbling & flowing the
only way I know how.



Lily

"Even at her young age, Lily loves to be surrounded by people and has yet to meet a stranger. She enjoys singing and being outside. If truth be told however, her favorite thing is her daddy's beard."

Chromosome 4p-, Wolf-Hirschhorn Syndrome

Miracle

“Miracle loves dressing up and her favorite color is yellow.”

Cornelia De Lange Syndrome

TYLER

Tyler is a very happy and energetic kid. Tyler enjoys playing outside with his older brothers, loves music and dancing. His favorite food is French Fries and he loves jellybeans!

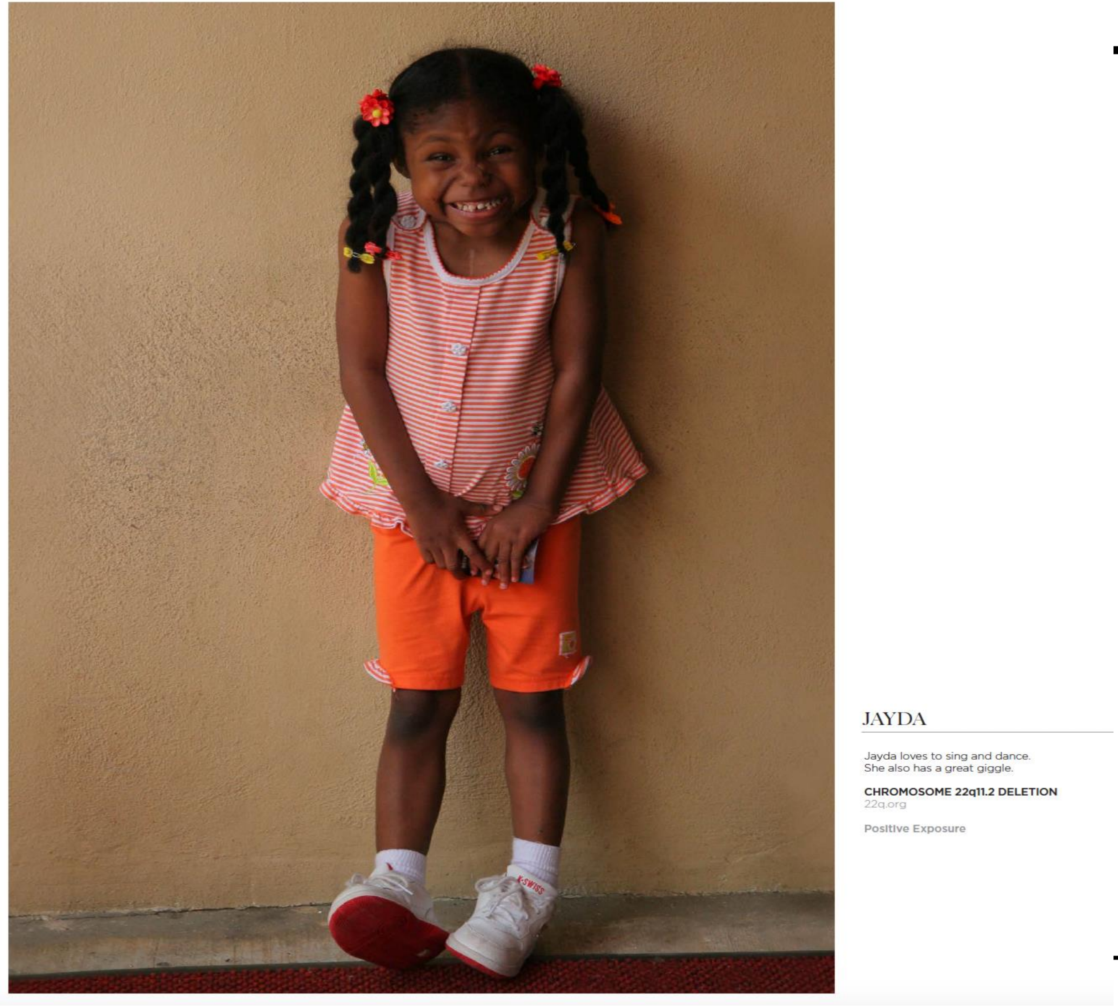
CONGENITAL MELANOCYTIC NEVUS
nevus.org

Positive Exposure

Tyler

"Tyler is a very happy and energetic kid. Tyler enjoys playing outside with his older brothers, loves music and dancing. His favorite food is French Fries and he loves jellybeans!"

Congenital Melanocytic Nevus



JAYDA

Jayda loves to sing and dance.
She also has a great giggle.

CHROMOSOME 22q11.2 DELETION
22q.org

Positive Exposure

Jayda

“Jayda loves to sing and dance. She also has a great giggle.”

Chromosome 22q11.2 deletion

AUSTIN

Austin loves to read, swim, watch movies and listen to music. He is kind, loving and hard working. He has a sense of humor that makes you laugh so hard your belly hurts.

FRAGILE X
fragilex.org

Positive Exposure

Austin

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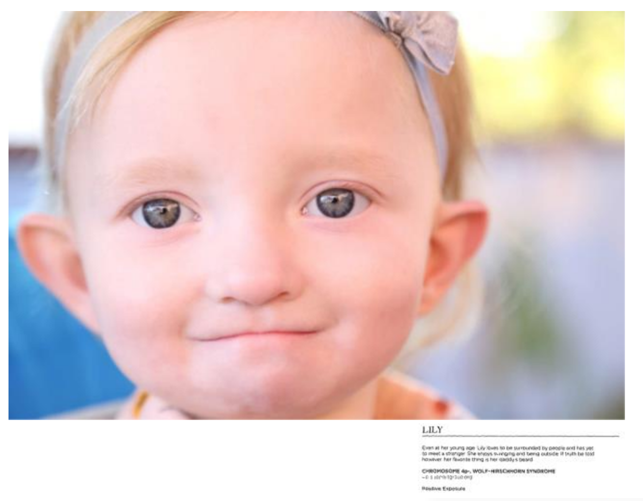
Fragile X

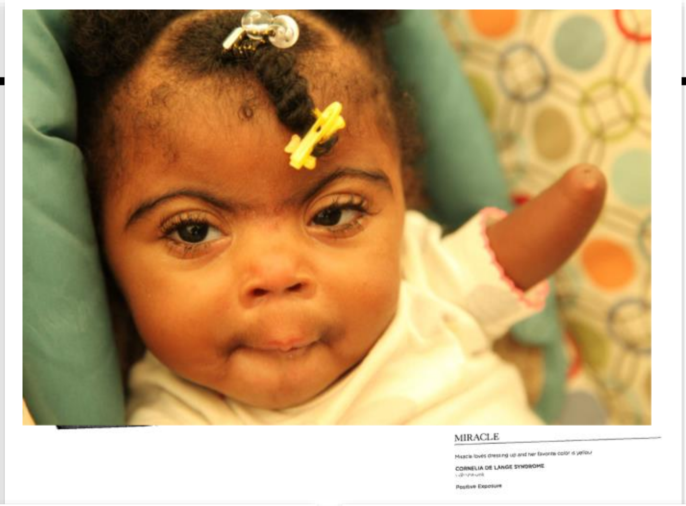


LILY

Even at her young age Lily loves to be surrounded by people and has yet to meet a stranger. She enjoys swinging and being outside. If truth be told however her favorite thing is her daddy's beard.

CHROMOSOME 4p-, WOLF-HIRSCHHORN SYNDROME
[illegible]

Positive Exposure

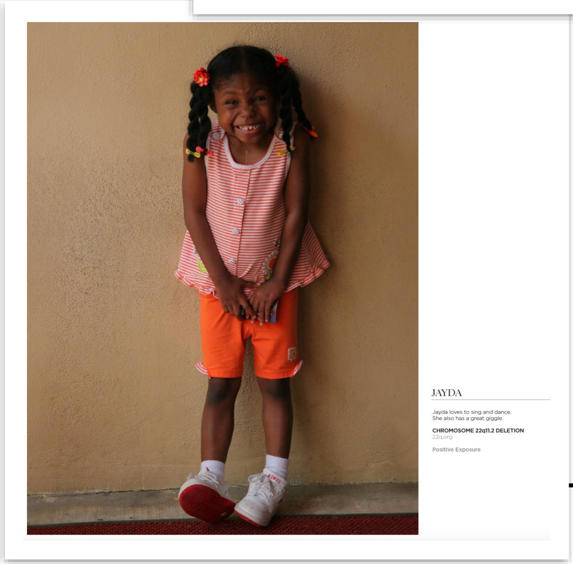


MIRACLE

Miracle loves dressing up and her favorite color is yellow

CORNELIA DE LANGE SYNDROME
[illegible]

Positive Exposure



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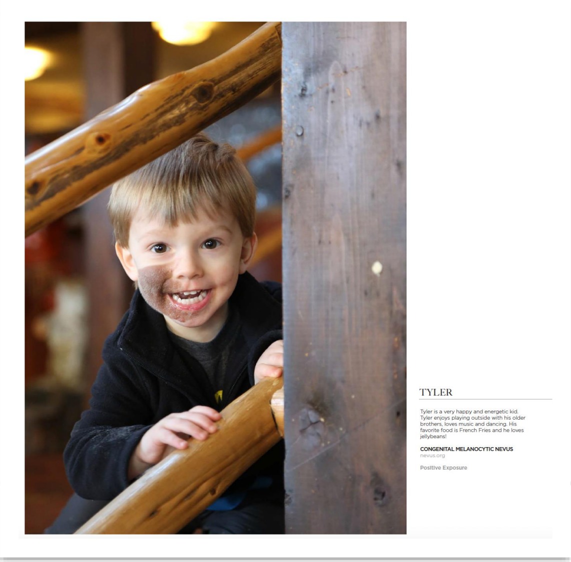

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CONGENITAL MELANOCYTIC NEVUS
nevus.org

Positive Exposure

Write about my eyes . . .

or

Write about my hair . . .

or

Write about my mouth . . .

Share writing and reflect as a group