

Explaining PHACE to family, friends, and your community

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Disclosures

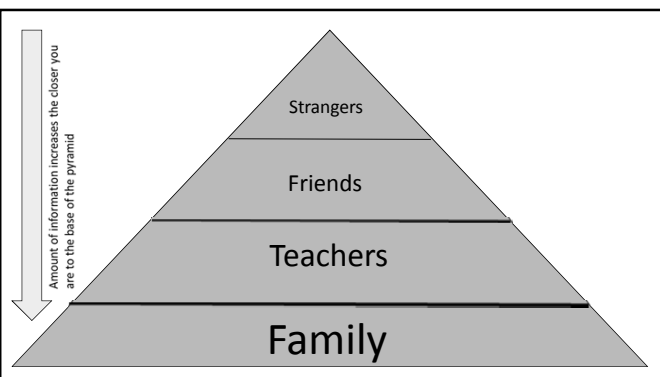
- No relevant financial disclosures
- I am a pediatric dermatologist
- I am not a psychiatrist or psychologist
- I am a parent

How to explain PHACE to others?

Family, friends, teachers, strangers

How many of you had heard of hemangiomas prior to your child's diagnosis?

How many had heard of PHACE?



Strangers

"the grocery store encounters"



Strangers



www.clipartof.com · 439149

Explaining PHACE to Strangers



Image from the Marconi Society

Explaining PHACE to Strangers

Take a deep breath

Smile

“Thank you for your concern for my child”

Or

“Thank you for asking”



Explaining PHACE to Strangers

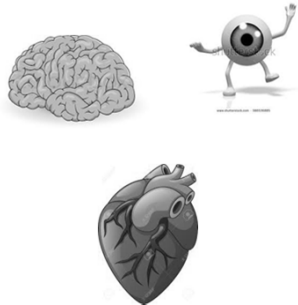
The Hemangioma

- It's a form of a birthmark
- What is a birthmark?
- This birthmark is made of a lot of blood vessels
- Early on the blood vessels are growing and making more blood vessels
- Later they stop growing and shrink down
- Fading with time
- Picture of segmental hemangioma

Explaining PHACE to Strangers

Beyond the Birthmark

- Sometimes with this type of hemangioma there are additional issues
- Other complications or problems with the brain, eyes, or heart

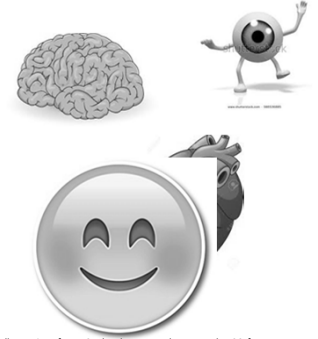


Illustrations from: Coulourbox.com, shutterstock, 123rf

Explaining PHACE to Strangers

Beyond the Birthmark

- Sometimes with this type of hemangioma there are additional issues
- Other complications or problems with the brain, eyes, or heart
- Thank you again for your interest in my child, have a great day!



Illustrations from: Coulourbox.com, shutterstock, 123rf, Amazon.com

Friends



itsourtree.com

Explaining PHACE to Friends

Beyond the Birthmark

- You may want to keep it simple, or be more detailed depending on the friend/neighbor
- You may receive a lot of unsolicited advice, good or bad, be prepared
- Educating those surrounding you and your child is important to socialization of your child



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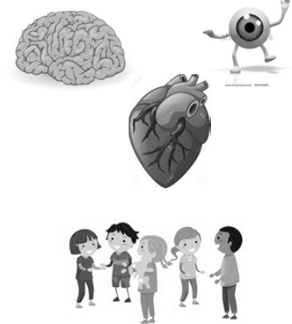
Teachers



Explaining PHACE to Teachers

Beyond the Birthmark

- Migraines
- Stroke
- Language delays
- Speech difficulties
- Delays in gross motor skills
- Hearing problems
- Other symptoms
- Peer relationships



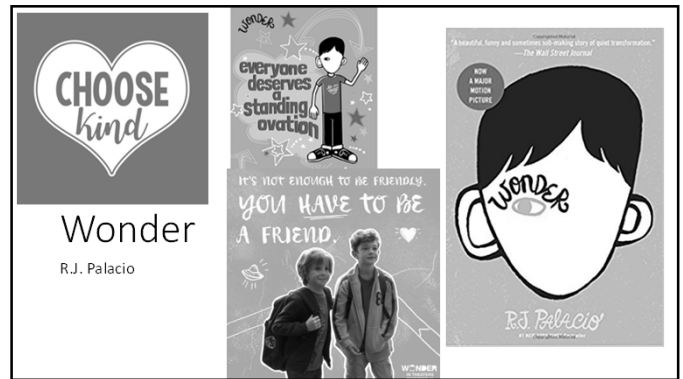
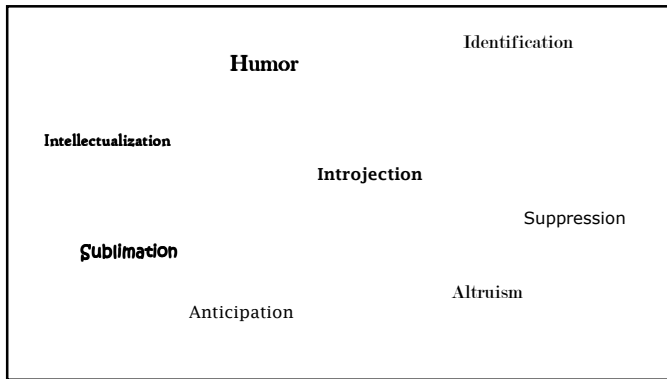
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Family



- P** **Posterior fossa** abnormalities and other structural brain abnormalities.
- h** **Hemangioma(s)** that are typically large and located on the skin of the head and neck area.
- a** **Arterial anomalies** of the head (brain) and neck. These can be arteries that are too narrow (stenotic) or dilated (aneurysmal) or the lack of normal blood vessels in the head and neck.
- C** **Cardiac defects**, with the most common being coarctation (narrowing) of the aorta or other aortic abnormalities
- e** **Eye anomalies** not caused by the growth of the hemangioma such as problems with the optic nerve

<http://www.phacesyndromecommunity.org/overview>



How will a facial birthmark affect my child?

Children with facial difference that affects >25% of their face are more vulnerable to stigmatism

Self-esteem starts to form around age 4 years

Studies that address the following questions in the next few slides:

- How does the hemangioma affect my child?
- How might teasing affect my child?
- What will other kids think about my child?

Masnari et al J Plast Reconstr Aesthet 2012;65:1664-70

Impact of hemangiomas

Table 5 Mean health-related quality of life scores for children age 12–15 years with haemangiomas and healthy children

| | Children Haemangioma mean n = 20 | Healthy children mean n = 986 |
|--------------------|--|----------------------------------|
| Physical symptoms | 26.6 ^a | 24.2 |
| Motor function | 30.7 | 30.1 |
| Cognitive function | 29.2 | 27.8 |
| Positive emotions | 14.7 ^b | 13.2 |
| Negative emotions | 12.2 | 11.8 |

Higher scores indicate a better quality of life. The Cronbach's alphas in our study population were moderate to good (ranging from 0.68 for motor functioning to 0.87 for cognitive functioning).

^a $p < 0.05$.
^b $p < 0.01$.

Table 6 Specific haemangioma questionnaire for children aged 8–15 years (n = 18)

| Children with haemangiomas aged 8–15 years | % agree | % disagree |
|---|---------|------------|
| 1. My life would have been different without a haemangioma | 19 | 70 |
| 2. I am different from other children because of my haemangioma | 4 | 84 |
| 3. I am stared at | 18 | 70 |
| 4. Public reactions make me aware of my haemangioma | 29 | 63 |
| 5. I had a feeling of self-blame | 0 | 96 |
| 6. I had a feeling of shame | 6 | 83 |
| 7. I try to hide my haemangioma | 10 | 81 |
| I am especially aware of my haemangioma when I am: | | |
| 8. Walking in the street | 6 | 91 |
| 9. Entering a public place | 9 | 87 |
| 10. At birthdays/visits from relatives | 4 | 93 |
| 11. Making new contacts | 17 | 74 |
| 12. At school | 11 | 83 |
| 13. Public reactions are making me nervous | 15 | 88 |

Replies n = 5.

Hoornweg et al J Plast Reconstr Aesthet 2009;63:1254-71.

Impact of hemangiomas

- Kids age 8-15 felt insecure in the past, but “grew out of it”
- Making new contacts, public reactions, and school are more problematic (even when the hemangioma is involuted)
- Majority of patients and parents are NOT negatively affected by the hemangioma

Hoornweg et al J Plast Reconstr Aesthet 2009;63:1254-71.

Teasing

- 5-55% rate of teasing among all children

- Study of 340 children with cleft lip/palate in Norway

Table 1 Reported teasing at different time points (cross-sectional) and across gender.

| | Total % (n) | Females % (n) | Males % (n) | χ^2 |
|---------------------|----------------|------------------|----------------|-------------------|
| Before age 10 | 39.0 (128) | 36.9 (48) | 40.4 (80) | 0.40 |
| Age 10 | 35.1 (115) | 38.5 (50) | 32.8 (65) | 1.09 |
| Before age 16 | 60.9 (162) | 71.2 (79) | 53.5 (83) | 8.44 ^a |
| Age 16 | 13.0 (40) | 17.4 (21) | 10.2 (19) | 3.36 ^b |
| Never | 24.6 (83) | 18.7 (25) | 28.4 (58) | 1.01 |
| One/two time points | 67.2 (227) | 69.4 (93) | 65.7 (134) | 3.03 |
| All time points | 8.3 (28) | 11.9 (16) | 5.9 (12) | 6.56 ^c |

^a $p < .05$.
^b $p < .01$.

KJB, Fergin, NLM, Stock / Body Image 16 (2016) 133–142

Teasing

- Teasing more significant risk factor than presence of a facial difference for decreased satisfaction with appearance and increased emotional distress

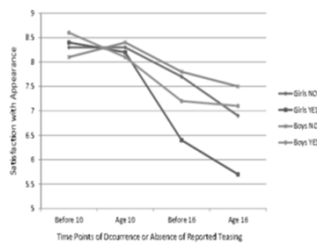


Fig. 1. Satisfaction with appearance measured at age 10 and 16 (CHASQ, range 0-10: low to high satisfaction with appearance) in terms of reported teasing (YES) or no teasing (NO) for females and males.

K.B. Penegar, N.M. Stock / Body Image 16 (2016) 133-142

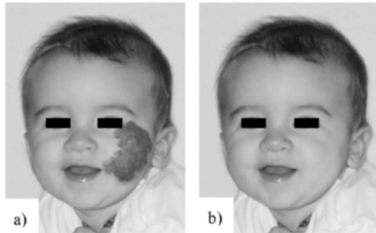
Teasing

- Adolescence is a key time to be aware of teasing and intervene
- This study suggests regardless of presence of facial difference, **teasing** is salient to the development of self-perceptions of satisfaction with appearance and emotional distress
- **Protective factors** (against teasing):
 - Positive peer relations
 - Perceptions of positive social experiences

K.B. Penegar, N.M. Stock / Body Image 16 (2016) 133-142

What do other kids think?

Q. Masnari et al. / Body Image 10 (2013) 515-523



- Photos of 12 children/infants with or without facial difference (congenital nevus, port wine stain, hemangioma)
- Children (344 total) ages 8-17 viewed photos (randomized) and marked if they had positive or negative impressions

What do other kids think?

- Children with facial difference rated as less likeable, less attractive, less happy, less good at school, less popular than without facial difference
- One item not significantly different: kindness
- Less willingness to interact or befriend children with facial difference
- Predictors of stereotypical attitudes:
 - Younger age: no interaction in past with someone with facial difference
 - Personal experience with hostile behavior imparted hostile behavior
- Concerns for kids with facial difference:
 - Less social interactions and poor development of social skills
 - Increase in social isolation and social anxiety

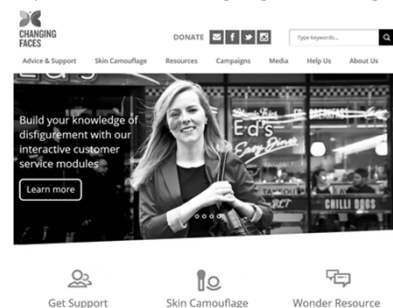
Masnari et al Body Image 2013;10:515-523

What do other kids think? How can you change it?

- Education by teachers and parents should help
 - Get in the classroom with students and teachers
 - Personal contact with children with facial differences
 - Presentation of oneself in social situations can directly affect first impressions and judgement can change as you get to know someone
- Teach positive social skills -- may reduce the stigma
- Teach coping skills to develop emotional resilience
- Social skills training to change the interpretation of others interactions/behavior and learned responses

Masnari et al Body Image 2013;10:515-523

<https://www.changingfaces.org.uk>



phace syndrome™ community

Search Site

ABOUT


PHACE

CONFERENCE

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CONTACT

OVERVIEW



PHACE Syndrome - Overview

PHACE Syndrome is the uncommon association between large infantile hemangiomas, usually of the face, and birth defects of the brain, heart, eyes, skin and/or arteries. It is an acronym that stands for the medical names of the parts of the body it often impacts:

P

h

a

c

Posterior fossa abnormalities and other structural brain abnormalities.

Hemangioma(s) that are typically large and located on the skin of the head and neck area.

Arterial anomalies of the head (brain) and neck. These can be arteries that are too narrow (stenotic) or dilated (aneurysmal) or the lack of normal blood vessels in the head and neck.

Skin defects of the face, such as the most common form of congenital cutaneous vascular malformation, the port wine stain.

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