



Transforming Lives:
The Adventure of Moving On:
Transition of Care for Individuals
with Cleft and Other
Craniofacial Differences

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Welcome and Introductions



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Presentation



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Disclosures

- **Dr. Brenda Louw** is employed full-time by East Tennessee State University, Johnson City, TN.
- **Dr. Linda Vallino** receives royalties from *Evaluation and Management of Cleft Lip and Palate: A Developmental Approach* (with Dr. David Zajac) and *Cleft Palate Speech and Resonance: An Audio and Video resource* (with Drs. David Zajac & Dennis Ruscello). She is employed full-time by Nemours/ A.I. DuPont Hospital for Children, Wilmington, DE.
- **Ms. Yelena Jennings** has no financial or nonfinancial disclosures.



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What you can expect this evening

To learn about the pathway of transition of care for the young adult with cleft lip and palate/craniofacial differences (CLP/CD).

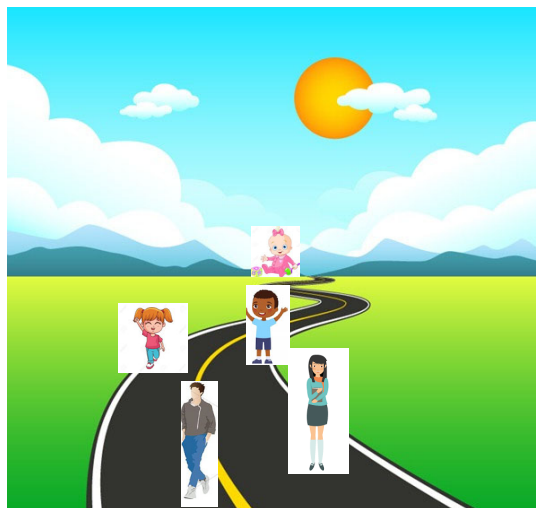
To learn about strategies for planning and preparing for the transition of care and other life transitions.

To learn about the experiences of a young adult with CLP/CD in moving on.



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Life is a highway....and we're movin' on



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What is Transition of Care?

Is **NOT** a graduation from any place or type of care.

"It doesn't go away." (Yelena)

But...

- a **process** of moving from pediatric to adult-centered care (spans over years)
- **gradual and purposeful** not static event
- **patient centered**

Optimal Goal: uninterrupted, coordinated, developmentally appropriate, psychosocially sound and comprehensive (Blum, 1993).



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As the child enters adulthood, things change...

For some, being 18 or 21 means "**Goodbye team!**"



Let's reframe that to:

Helloooo and Welcome:

- New services within the existing team
- A new adult-centered team
- Community practitioners
- Independence



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Is transition of care discharge from care?

NOPE–It is not

- Don't let people tell you that further treatment is unavailable after leaving the team.
- Services **are** available on an adult-centered team or by individual providers within your community



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Difference between Types of Care

Pediatric-Centered Care

- Focus on family
- One-stop shop, rich in resources
- Providers talk to your parents and you about your care
- Providers may spend more time with you and your family
- Relationship with providers may be stronger (you've spent a long time with them)
- If under 18, parent involvement and consent may be needed
- Parents advocate for/with you

Adult-Centered Care

- Focus on individual – independence
- May need to find your own community and specialty resources in other locations
- Providers talk directly to you and expects you to make decisions about care
- Appointments may seem short
- Relationships may take time to develop
- If over 18, you must grant permission for parents to be in the room, see test results, discuss findings, medical record access
- You advocate for yourself
- You're not the oldest one in the waiting room

<https://cshcn.org/adolescent-transition/pediatric-versus-adult-health-care/>



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Shared Concerns of Parents and Young Adults

May be apprehensive about transition to:

- moving to adult care providers, college, **work**, new social settings

Can find it hard to:

- let go
- strike a balance between protecting their child, offering support, and facilitating independence

Are concerned about:

- getting the services they need/want (i.e., dental, medical/surgical, mental health, speech)
- being able to pay for these services



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On leaving the team: What are parents saying?

"It came so soon."

"It just stopped."

"I wasn't ready."

"I had been with this team for so long"



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Leaving the team: What are young adults with cleft lip & palate/craniofacial differences (CLP/CD) saying?

I was literally kicked from the state system. I was in college and had just turned 18 and the dr. said, "so what else do you want from me?"

To be honest there needs to be a specific group of surgeons solely based on helping adults with ongoing life issues related to their clefts. No more kid office visits. No more patching up an adult with what you would do to a child. That's the most frustrating!

Adults really are just now finding their voices and realizing that 18 was not the end...when complications arise you can find the right surgeon and speak well and with passion about the things you need help with.



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Let's hear from Yelena...

Tell us about your experience on a cleft palate team and how is it different now that you are an adult?



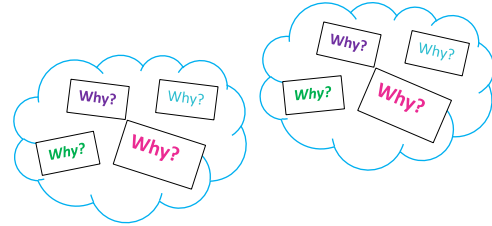
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But why????? (do I have to leave my team?)

Because...

- "Because I was booted out." (Yelena)
- It makes sense.
- Need to find providers who can respond to your health care needs and relate to you at this phase in your life.
- Even if an adult-cleft team is available, you will transition to an adult approach for your care within the practice.



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Let's think about transition of care

Understand	Challenge	Shift	Empower	Goal
Understand transition happens	Challenge for providers, parents, young adults	Shift thoughts and actions to include what the young adult wants/needs	Empower the young person to support themselves	To improve and enhance quality of life



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Why is Transition of Care Important?

To ensure health care continuity and prevent a treatment gap

To prevent poor outcomes

To ensure quality care

To reduce costs



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Transition of Care

Patient-centered

Whole-person care

Choices and collaboration

Quality of life

Health-related quality of life

Well-being



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Key to Successful Transition

- Embracing transition – young adult, parents, and providers
- Including psychosocial providers in the process
- Balancing participation by young adult, parent and team providers
- Focusing on patient centeredness



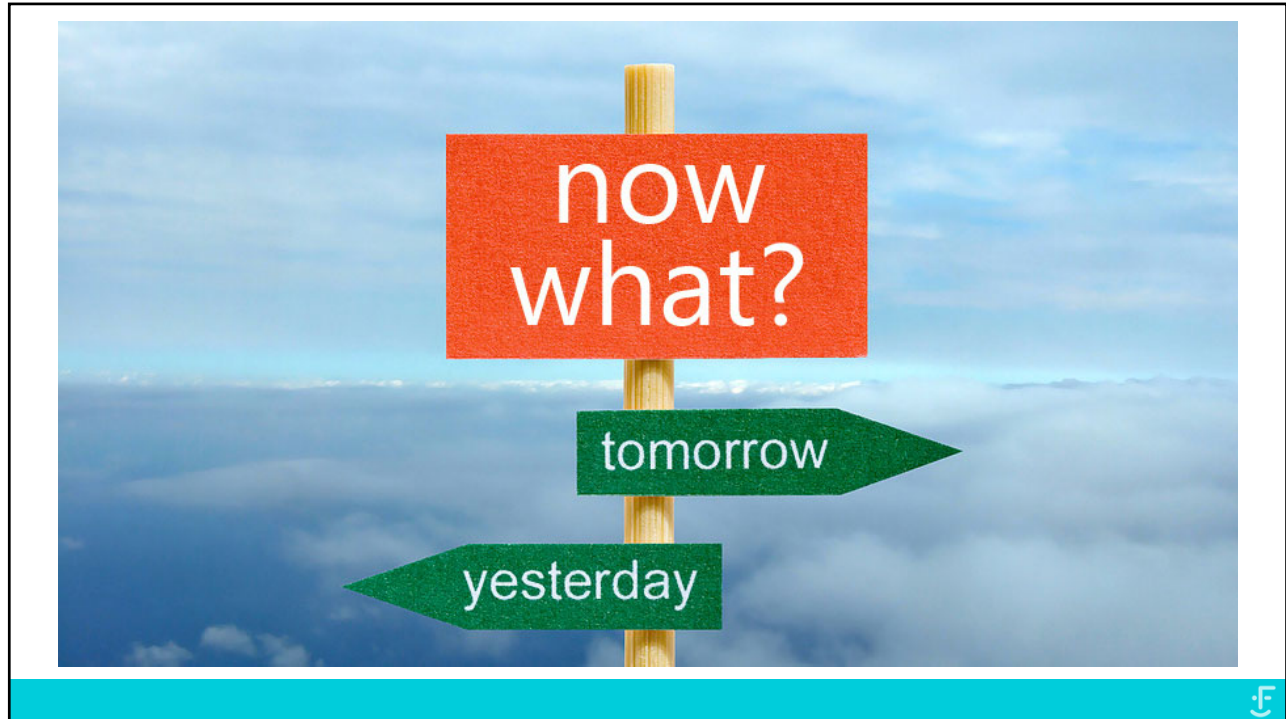
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For the parents/caregivers regarding transition of care

Start	Start talking earlier than later – teach your child skills that will enable them to manage successfully on their own – be open and listen
Expect	Expect some stress, understand challenges of change
Recognize	Recognize how roles will change (from overseer of care, to consultant to support) – shift gears

See handout for more tips

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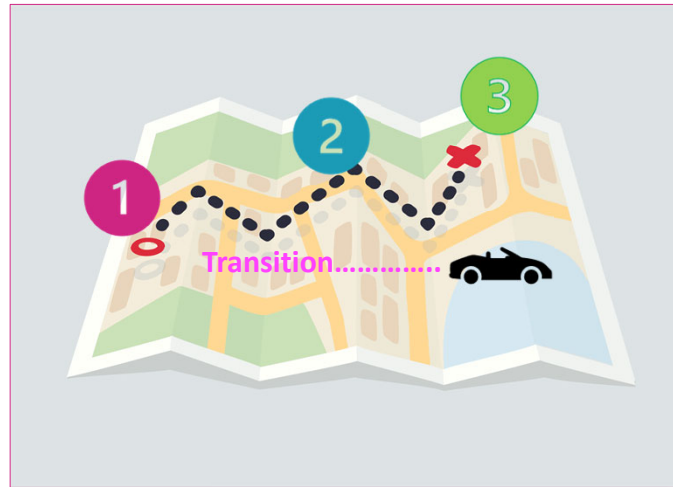


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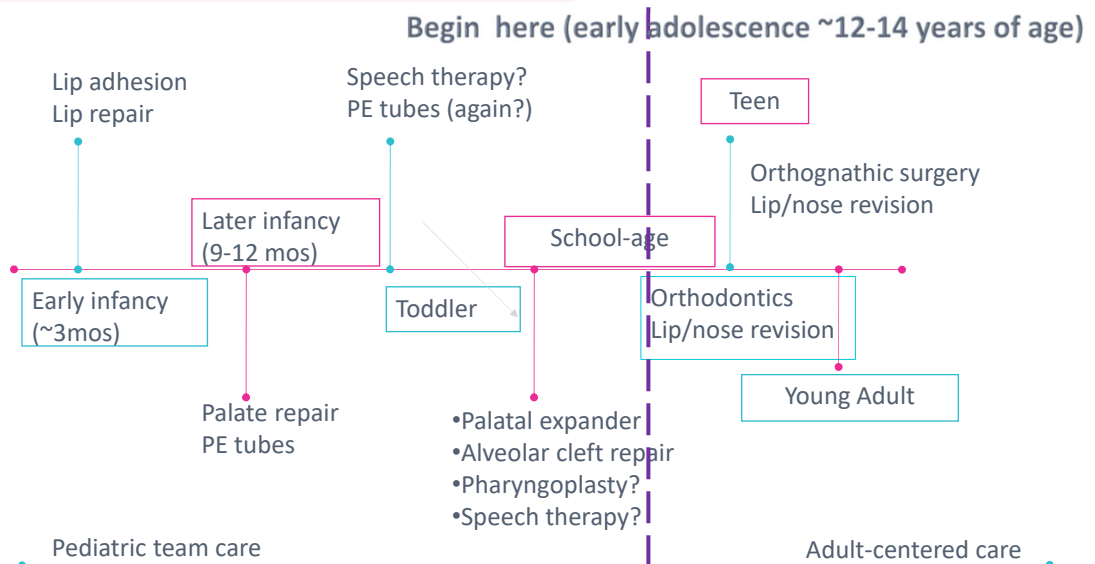
Road Map to Transition of Care

- 1 Preparation
- 2 Journey
- 3 Arrival



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When do we move? Preparation



Vallino and Louw, 2016

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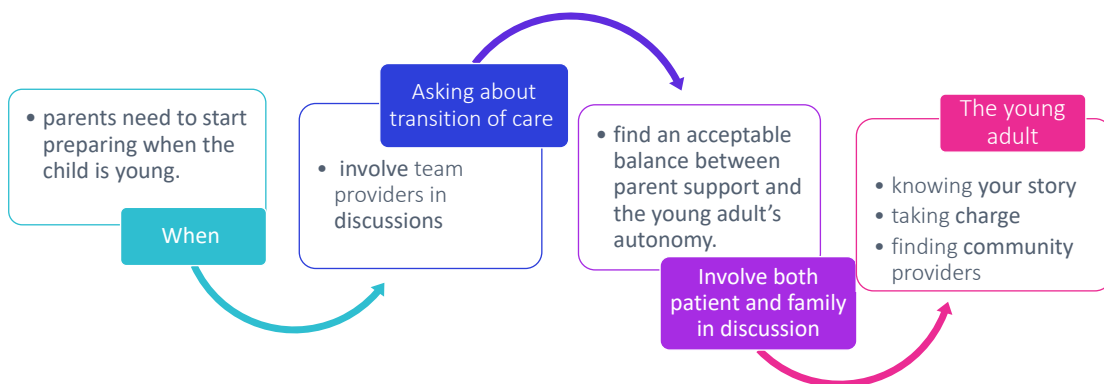


Preparation: Roadside Assistance



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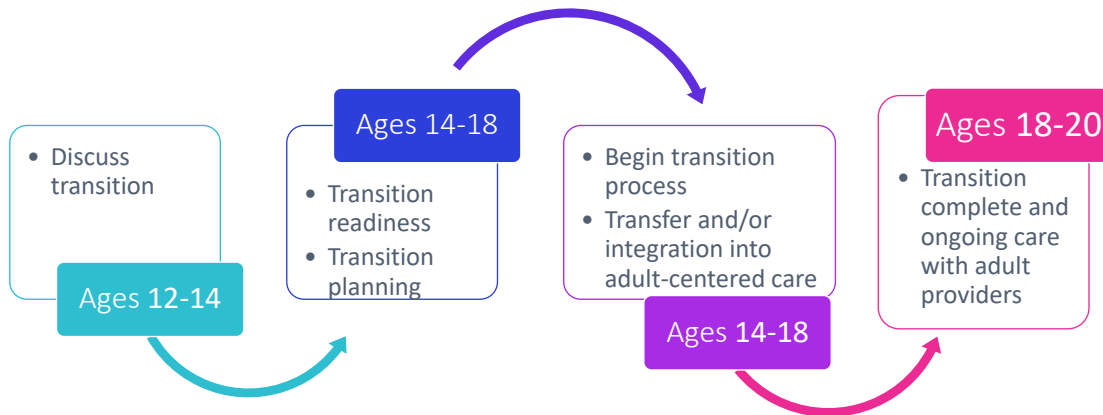
Getting there...Preparation



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Ages: Transition of Care



Adapted from: White et al., 2018



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Three questions for Yelena

1. Was it challenging transitioning from a pediatric team to adult services?
2. Was there an adult team available to you or did you have to seek out community providers?
3. Who was your support?



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Making it a smooth transition: Knowledge and Skills

- Make healthcare a priority
- Being able to ask for help when you need it
- Share information and life goals with new healthcare providers so that you all can be partners in your care
- Learn how to become an effective self-advocate...this will help you achieve your goals (healthcare, school, career)



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About your appointment

Know that you will be involved
in the conversation



- Know what appointment(s) you need to make
- Make your appointment even if it is difficult.
- Think of what you want/need before the visit.
- Prepare a list of questions before you go to the visit.
- Practice a mock discussion at home with your parents.

Photo: <https://www.cdc.gov/childrensmentalhealth/features/health-care-transition-gaps.html>



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To the adolescent... What are your responsibilities at your appointment?

- ✓ Check into the appointment yourself.
- ✓ Sit near the provider (not your parent).
- ✓ Make sure you can describe your facial difference, treatment, needs and goals.
- ✓ Ask questions (about your problem, concerns).
- ✓ Make sure your provider listens and hears you.
- ✓ If you don't know the answer to a question, it is OK to refer to your parent.
- ✓ Know that an interpreter may help you follow the conversation more easily.



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Suggestions for questions to providers

Talk about current concerns and wants/needs, including:

- Structure (i.e., nose, lip, teeth)
- Function (i.e., speech, eating, smiling)
- Psychosocial (i.e., explaining facial difference, entering a new situation)



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How do you keep track of all of this?



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What can parents do to help with keeping track and organizing all your care?

Yelena says...



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Preparation: MyHealth 3 Sentence Summary (SickKids)



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My Healthcare Passport (currently under construction, Vallino and Louw, 2022)

The graphic displays a green cover for the 'My Healthcare Passport' and a preview of its contents:

- Identifying information** (name, address, phone)
- Diagnosis** (Medical/Dental Information)
- Other Information** (i.e., medicines)
- Surgeries/Dates**
 - Cleft Lip 1/1/1996
 - Cleft Palate 9/1/1996
 - Alveolar bone graft 1/1/03
 - Buccal flap 2/2/2004
 - Upper jaw adv 1/1/2021
 - Nasal revision 1/2/2022
- Important Phone Numbers**
 - Dentist 123-4567
 - Orthodontist 891-0111
 - PCP 198-7654

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Preparation: Checklists are important

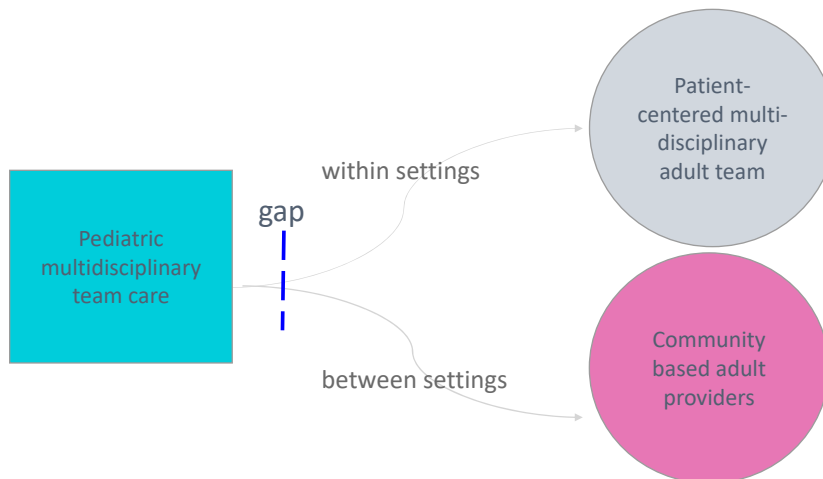
What I already know

What I need to know

Do I need help to do this?

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The Journey: the movement a person makes between health care practitioners



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Adolescents and Young Adults: Your responsibility

✓ Know how to contact the providers you need.

✓ Schedule your own appointments.

✓ Learn about health insurance and how to obtain it.

✓ Follow through on appointments and recommendations.

Develop skills to self advocate.



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Supporting Young People with CLP/CFD with Additional Challenges

Assess for transitional readiness – several tools available

May need a proxy to take on role of primary medical decision making

Work on long-term needs (medical/dental, financial, work, overall care)

Assist the young adult, when appropriate, in building decision-making skills

Establish health care supports



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The Arrival

Question: How do we measure transition success?

Answer: No one really knows.

Successful transition is complex (challenges are clear, solutions are not so clear)

(Hart, 2020)

Improved measurement for transition of care is a scientific priority (Eunice Kennedy Shriver National Institute of Child Health & Development 2020-2024)

We need reliable measures across the whole transition from age 12–26 (Hart, 2020).



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Future Directions

Data/Information about:

- Health outcomes
- Satisfaction with care
- Cost and resource utilization
- Challenges in getting care
- Setting of care delivery (i.e., adult team, individual)
- Length and timing of Transition of Care (i.e., age at initiation)



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Let's hear from Yelena more time...

1. How did you navigate transition of care?

2. Do you feel you can advocate for yourself and for the services you need?



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Transition of Care



Yesterday

Preparation:
thinking about
immediate and
future concerns



Today

Journey:
transition itself
and moving
on



Tomorrow

Arrival:
reaching goals
and outcomes

Adapted from Nguyen and Gorter, 2013



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Resources

- <https://acpa-cpf.org/wp-content/uploads/2018/05/As-you-Get-Older.pdf>
- <https://ccakids.org/>
- <https://www.myast.org/communities-practice/pediatric/web-resources-transition-adult-care>
- <https://www.sickkids.ca/en/patients-visitors/transition-adult-care/>
- Virtual Support Groups - myFace <https://www.myface.org>



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Selected References

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5. Vallino, L. D., & Louw, B. (2017). We've got some growing up to do: An evidence-based service delivery model for the transition of care for the young adult with cleft lip and palate. *Perspectives of the ASHA Special Interest Groups*, 2(5), 4-17. <https://doi.org/10.1044/persp2.SIG5.4>
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Questions & Answers



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Closing Remarks



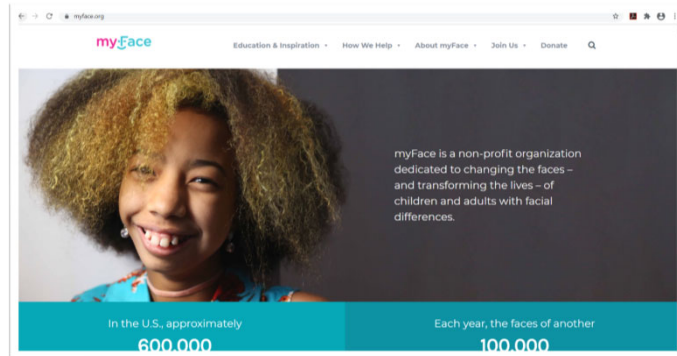
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For additional information and resources
visit [myFace.org](https://myface.org)



Or email us at
info@myface.org



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Upcoming Events at myFace

Join us on
Wednesday, May 11th at 6 PM ET
for a discussion on finding joy in your journey
growing up with a cleft or facial difference!

Register at:
www.myface.org/mystory/

myFace myStory
S1 E12: FINDING JOY IN YOUR JOURNEY
GROWING UP WITH A CLEFT OR FACIAL
DIFFERENCE
May 11, 2022 at 6pm ET
myface.org/mystory



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Upcoming Events at myFace

Join us for the next webinar in the *Transforming Lives Webinar Series* for a discussion on preparing teenagers for orthognathic (jaw) surgery!

To learn more, and to register for this webinar, please visit www.myface.org/surgerywebinar

myFace
TRANSFORMING LIVES
WEBINAR SERIES

Preparing Teenagers for Orthognathic (Jaw) Surgery

Leanne Magee, PhD
Children's Hospital of Philadelphia

Jesse A. Taylor, MD
Children's Hospital of Philadelphia

Funding generously provided by The Louis J. and June E. Kay Foundation

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Upcoming Events at myFace (cont.)

Join us on **Monday, May 2nd at 6 PM ET** for musical performances, awards, storytelling, and a benefit for the craniofacial community.

You can participate either in person in New York City, or online.

Register at:
www.myfacecelebrates.org

myFace
Celebrates...

Sharing messages of *hope, resilience and community* through musical performances and storytelling to benefit the craniofacial community

Starring

GRACE, 15 SAMIR, 12 ANA, 15 KAYLEE, 15

MONDAY MAY 2 2022 Guastavino's 409 East 59th Street New York, NY 10022 *Festive Atmosphere* myFaceCelebrates.org

*A livestream broadcast starting at 7:30pm ET will be available for those who cannot attend the in-person benefit.

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Thank You

Please complete the evaluation at <https://www.myface.org/evaluation>