



Transforming Lives:
Providing Strategies to Support
Families Impacted by
Craniofacial Conditions

myFace is pleased to collaborate with the American Cleft Palate Craniofacial Association (ACPA)
to present this educational program



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Welcome and Introductions



Stephanie Paul
Executive Director
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Presentation



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Disclosures

- **Meredith Albert, PhD**, has no disclosures
- **Janine Rosenberg, PhD**, has no disclosures

Objectives

- To define stress and the barriers to self-care
- To review strategies that promote the well-being of caregivers, with a focus on stress management and self-care practices
- To address the unique needs and challenges of siblings
- To discuss communication strategies that foster a supportive environment that promotes all family members' well-being
- To review family support options, including counseling, support groups, and respite care



<https://www.samatters.com/three-types-stress/>



<https://www.vicisis.ca/cope/>



<https://www.creative-tim.com/blog/education/ways-to-communicate-with-customers-to-achieve-success/>

Stress Defined...

- Defined as a state of worry or mental tension caused by a difficult situation (World Health Organization).
- Stress is a normal reaction to everyday pressures, but can become unhealthy when it upsets your day-to-day functioning.
- Stress involves changes affecting nearly every system of the body, influencing how people feel and behave.
- By causing mind–body changes, stress contributes directly to psychological and physiological disorder and disease and affects mental and physical health, reducing quality of life (American Psychological Association).
- Stress can affect people of all ages, socio-economic backgrounds, race, religion and gender.
- Stress can look different for different people.



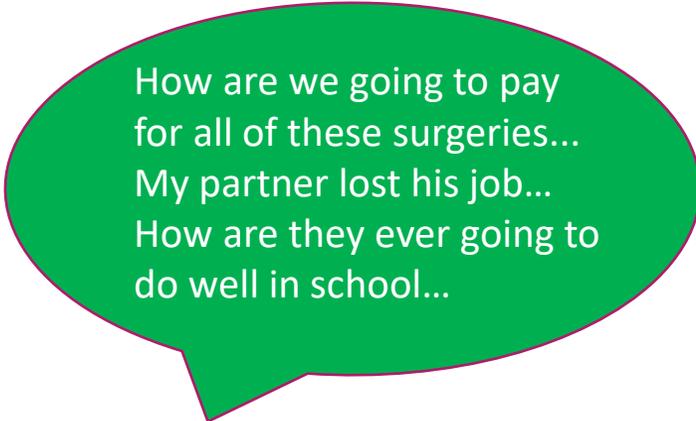
Picture from Psychology Today

Two Types of Stress

- Acute: short-term stress (project at work, assignment for school, flu, problems with the house, argument with partner)
- Chronic: long-term stress (management/adjustment of chronic medical conditions, mental health diagnoses, management of learning/intellectual disabilities, financial, social difficulties)

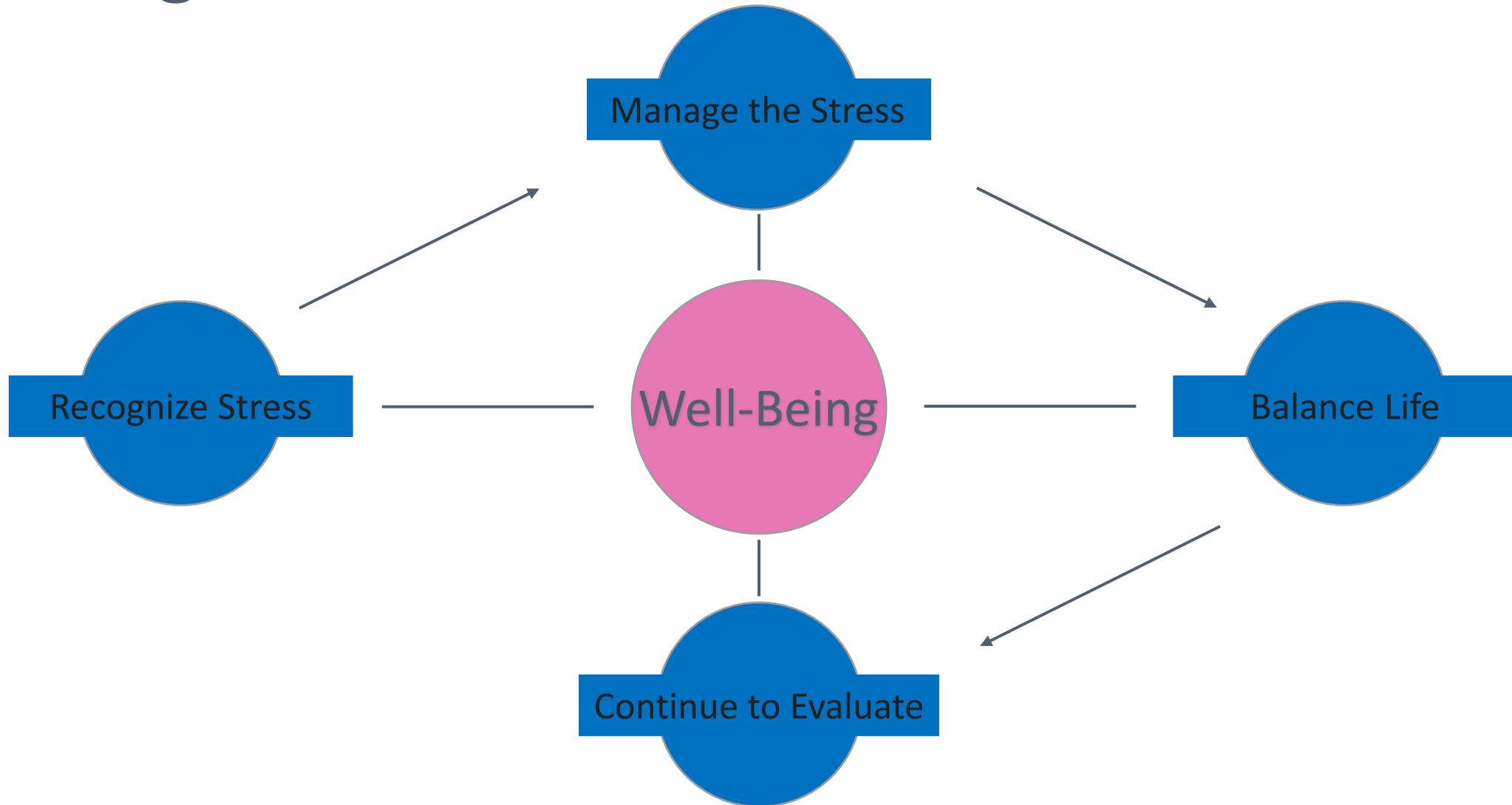


The toilet broke...
Sally has 3 tests this week...
I am going to miss work
because of this cold....

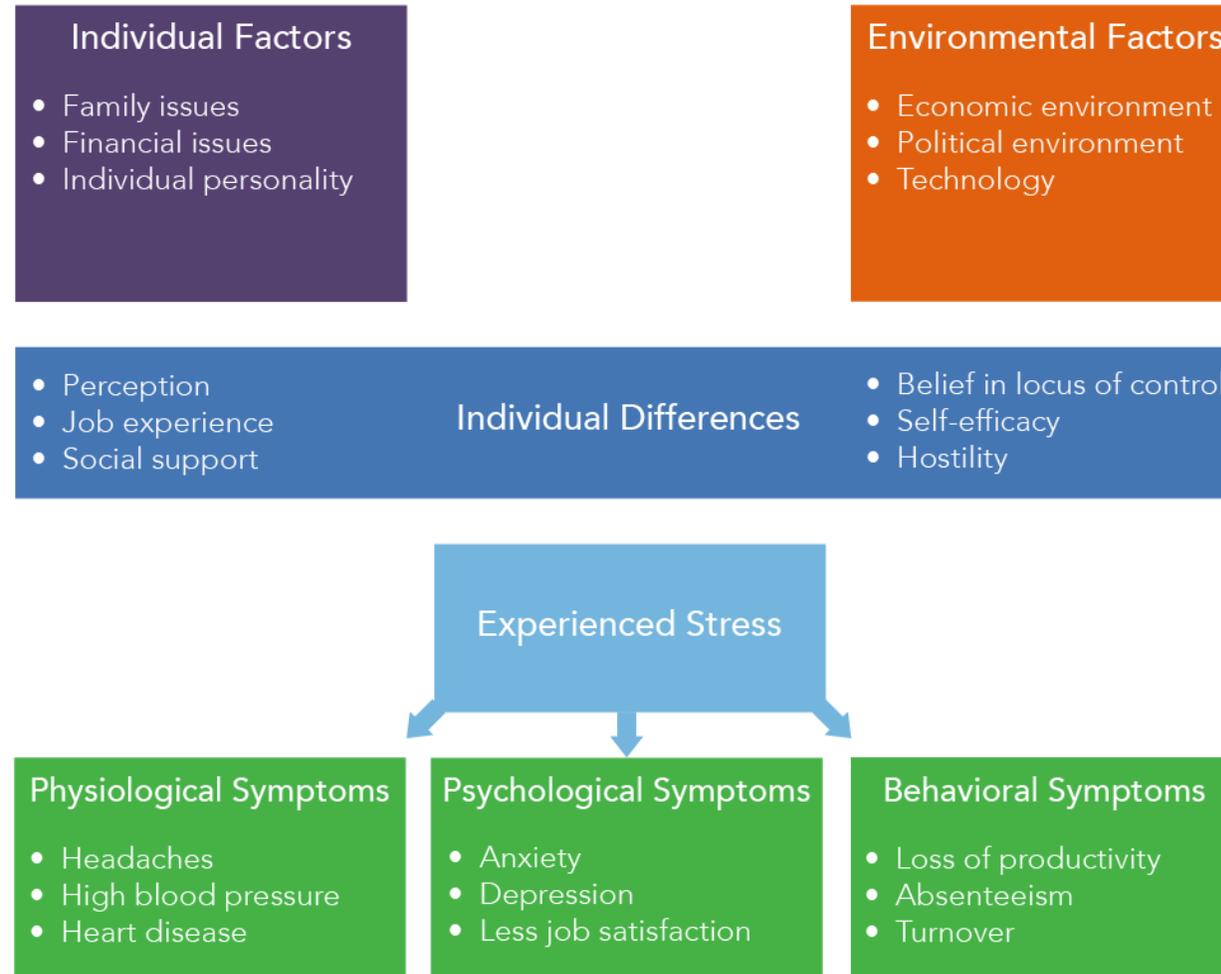


How are we going to pay
for all of these surgeries...
My partner lost his job...
How are they ever going to
do well in school...

Management of Stress

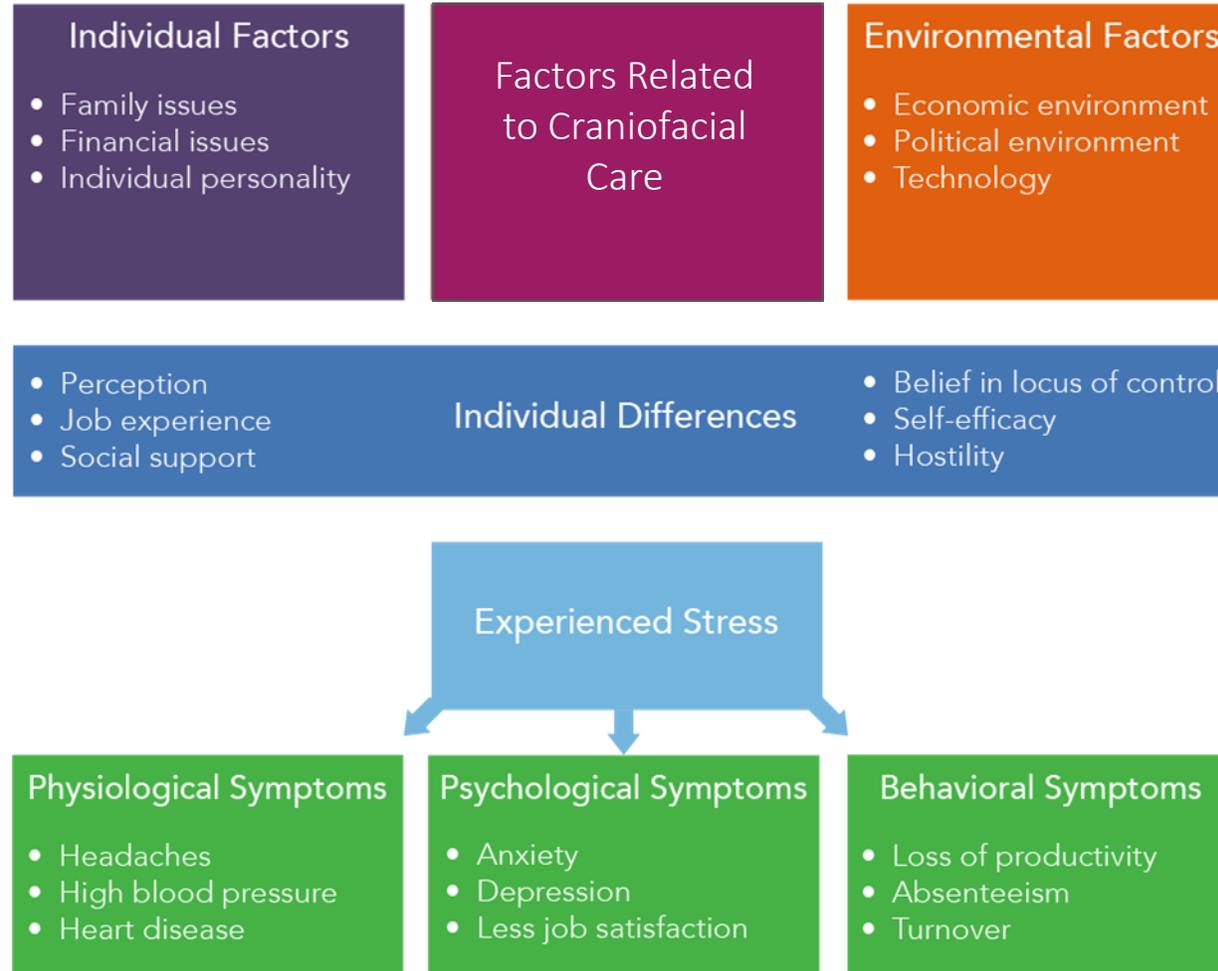


General Model of Stress



<https://courses.lumenlearning.com/wm-organizationalbehavior/chapter/sources-of-stress/>

Factors Specific to Craniofacial Conditions



Burdens & Factors Related to Craniofacial Care

- Prenatal, caregiver, family adjustment after diagnosis
- Basic care: Feeding, hearing, sleeping, reflux, breathing
- Medical Care: Craniofacial care team appointments; surgeries/treatments; orthodontic care; other doctor appointments
- Therapies: Speech therapy, occupational & physical therapies
- Mental Health Care for both caregiver & child
- Logistics: Transportation, absences from school and work
- Financial burdens; insurance coverage
- Advocating for services in school and community
- Management of learning services
- Interventions for bullying/teasing, social support for your child
- Caregiver responsibility for management of care
- Obtaining support for caregivers
- Transition to adult services



What is YOUR role?

- The burden of care falls on everyone
 - Patients
 - Parents/Caregivers
 - Extended Family
 - Siblings
- Avoid uneven distribution



DIFFERENT FAMILIES
Same Love



<https://kidsfirstofflorida.org/creating-a-blended-family/>

Self-Care



- Definition of Self-Care: “The ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a health-care provider.” (WHO)
- “When it comes to your mental health, self-care can help you manage stress, lower your risk of illness, and increase your energy. Even small acts of self-care in your daily life can have a big impact.” (NIMH)

Barriers to Self-Care

- Awareness of and Access to Resources: services for medical care, development, social & education
- Health Disparities: culture, language, and socioeconomic status can impact access to care
- Time to take care of yourself (i.e., caregivers eating, sleeping, showering & cleaning the house)
- Finances/Insurance Coverage
- Support from Spouse/Partner & Extended Family
- Proximity to Craniofacial Team & Additional Providers
- Caregiver physical, medical, and mental health



How Parents Engage in Self-Care?

- If you don't take care of yourself, you can't take care of others
- **Acceptance** of diagnoses and prognoses
- Set **realistic expectations** for you and your family; know your limitations and set boundaries
- **Ask for help!** from family, friends, community, medical providers, therapists, & educators
- Take pictures, document & **share your story** with others
- **Carve out time** when planning a daily schedule
- **Develop a coping toolbox:** e.g., Engage in desirable activities/hobbies, call friends/family, physical activity, take a timeout (find a quiet space alone, take a shower/bath), journaling/logging
- **Relaxation/Meditation:** e.g., YouTube (Honest Brothers), Apps (Calm, Breethe, Headspace), Podcasts (Mindful in Minutes Meditation)
- **Mental Distractions:** e.g., Read books, do yoga, listen to music
- Seek your own **therapy** and local **support groups**
- Seek resources and support from **websites** such as myFace, ACPA
- Seek out low cost or **free resources** (Ask treatment providers, educators for resources)



Sibling Stress

- Siblings are affected too!
- Burdens on Sibling:
 - Understanding sibling's diagnosis in a developmentally appropriate way
 - Time and attention placed on sibling with craniofacial diagnosis
 - Impact on interpersonal functioning (i.e., friendships, exposure to bullying/teasing due to sibling's diagnoses)
 - Changes/restrictions in daily schedule
- Recognize Burdens on Siblings. Are there CHANGES in:
 - Mood – anxiety, depression, withdrawal
 - Behavior – acting out or attention seeking behavior
 - Daily functioning (sleep/appetite)
 - Attachment to parents, changes in school performance



<https://www.theguardian.com/lifeandstyle/2023/nov/20/how-to-survive-sibling-rivalry-child-and-parent>

Strategies to Support Sibling Stress

- Provide space for siblings to talk
- Make sure to give siblings attention/regular check-ins
- Provide education and language about craniofacial differences
- Role plays, readings, pictures/images (related to craniofacial condition)
- Involve siblings in craniofacial care/appointments
- Mental health care for siblings – e.g., therapy, support groups



Support for the Entire Family

- This is essential!
- No one in the family functions in isolation
- Find balance



<https://www.bgcsfv.org/family-preservation-program>

Strategies to Foster Communication in the Family

- Identify and be aware of your family's specific culture/beliefs/backgrounds
- Set roles and expectations for medical care (i.e., who is feeding, scheduling & attending to doctor appointments, caring for siblings)
- Listening versus hearing
- Try not to be defensive, accusing, or overprotective
- Use of "I statements"
- Communicate needs for self and family to others clearly
- Older children: Set a time for family meetings to check in
- Keep all family members in the loop
- Problem solve to encourage goals are met in a consistent way
- Everyone needs to be on board with the plan
- Communication is not limited to nuclear family. Include your extended family
- Seek outside support to promote communication (i.e., craniofacial team, family therapist, pediatrician)



An Example of A Child and Caregiver Resource - Cellie Coping Kit

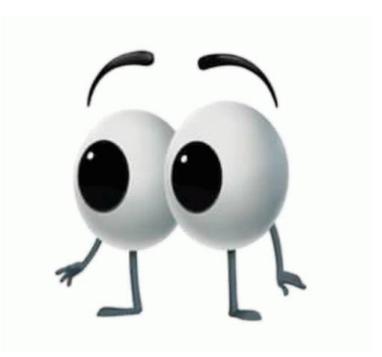
- **Cellie Coping Cards and parent booklet:**
 - Created by the psychology team
 - Provides psychoeducation and cognitive behavioral coping techniques to address children's craniofacial-related and socioemotional concerns as well as how caregivers could support their child through these challenges
- **This is just one example of a resource** that provides additional support for families.
- **Ask your craniofacial team for resources available!**



University of Illinois – Hospital Craniofacial Center in Chicago

<https://www.healthcaretoolbox.org/cellie-coping-kit>

Outside Support: Where to find it?



- **Pediatrician:** First point of contact for referrals and services (Early Intervention, Therapy Services, Respite Services, Case Management)
- **Schools:** 504 Plan, Individualized Education Plan, Teacher Support, General Academic Support, Therapy Support, Social Work Support, Advocacy in Schools
- **Craniofacial Team:** Advocacy, Referrals (i.e., Therapies, Orthodontia, Dental, Sleep, Genetics) Psychoeducation, Therapy Services (Site Dependent)
- **Support Groups:** Social Media Groups, Virtual Support Groups, Live Support Groups, Family to Family Support

Sample Online Resources

- myFace (<https://www.myface.org/>)
- ACPA (<https://acpacares.org/>)
- Facebook Groups (Cleft Mom Support; Cleft Lip and Palate Association)
- Examples of Center-Specific Resources (www.pkpatelmd.com;
<https://www.nationwidechildrens.org/specialties/cleft-lip-and-palate-center>;
<https://www.seattlechildrens.org/clinics/craniofacial/>;
<https://www.chop.edu/centers-programs/craniofacial-program>)

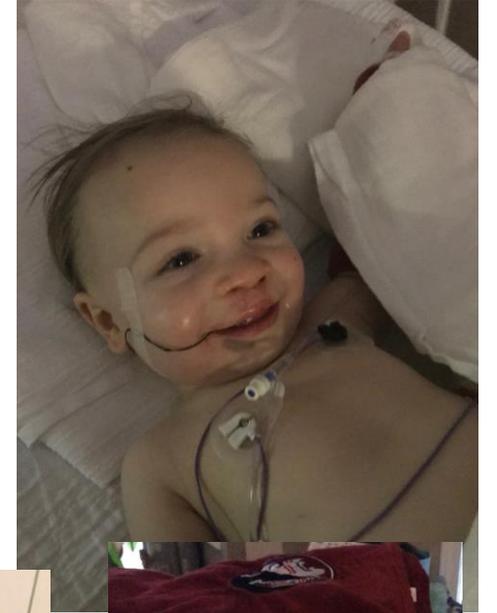
THANK YOU



Terilyn and Evan's Cleft Journey



Highs and Lows



Advice



Stress Reducers

- Being open about your journey and your story
- Having a good support system (spouse, family, friends)
- Don't be afraid to ask for help/teach others
- Finding time to spend away from the situation or to step away
- Music – finding a theme song
- Knowing that you are human (you will cry, you will be angry) – IT'S OK!
- Building CONFIDENCE in your kiddos
- Seeing your child's strengths, which makes you stronger

Contact Information:

Email: cleftiecutiesmiles@gmail.com



Closing Remarks



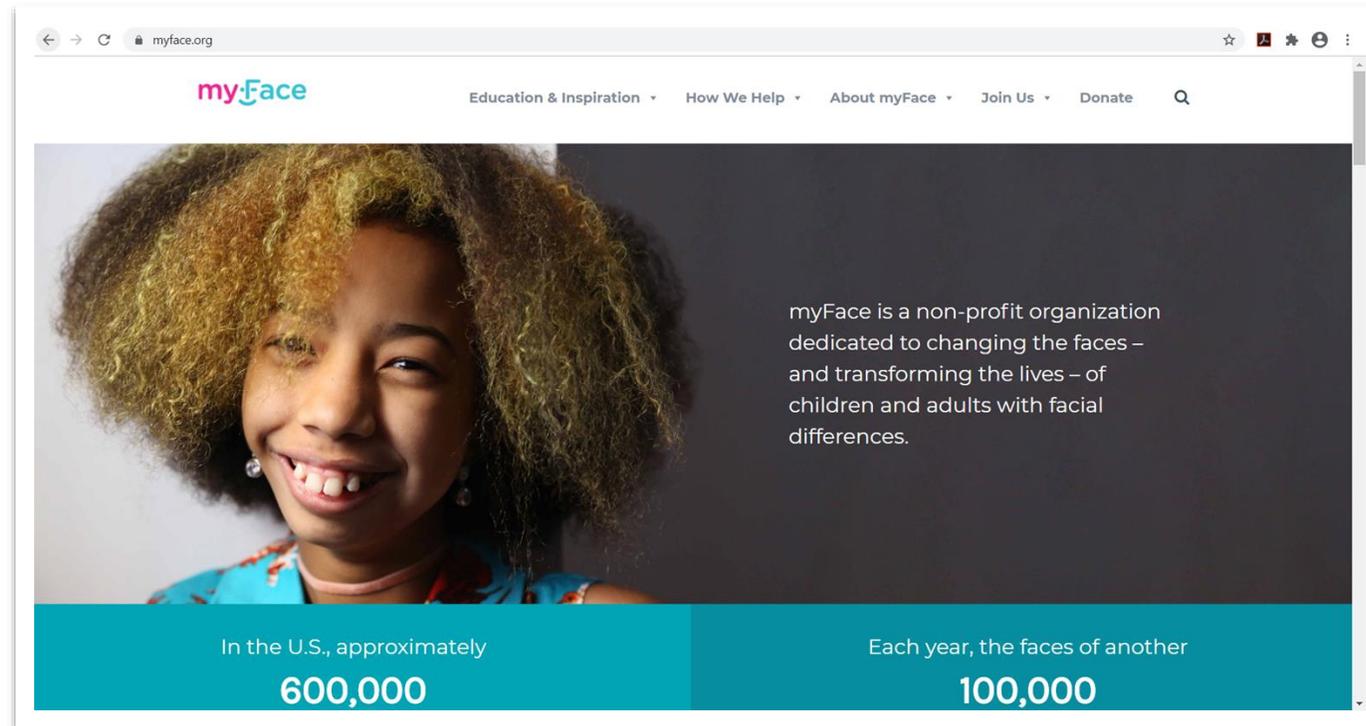
Stephanie Paul
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For additional information and resources
visit [myFace.org](https://myface.org)



Or email us at
info@myface.org



Upcoming Events at myFace

A new episode of our *myFace, myStory* podcast will debut on **February 15th** on all podcast platforms + YouTube

The episode will feature a conversation with Kathleen Watt, who will share her experiences as an opera singer, a survivor of facial cancer, and a memoirist.

Register at:

www.myface.org/mystory/



**Rebuilding a Life
After Facial Cancer**



Dina Zuckerberg



Kathleen Watt

my face
myStory

Virtual Support Groups at myFace

- myFace offers FREE virtual Support Groups for individuals with facial differences, and for their parents:
 - Parent Support Groups (in English and in Spanish)
 - Prenatal/Infant Parent Support Group
 - Adult Support Group
 - Adolescent Support Group (ages 14–18)
 - Drama Therapy Group for Youth (ages 10–14)
- Sessions are 1 hour in length, meet once or twice per month, and take place on zoom
- Groups are therapist-led, or peer-led
- For more information, or to join a group, please visit our website at: www.myface.org/online-groups



Upcoming Events at myFace

Join us on

Wednesday, June 5th at 6:30 PM ET

for musical performances by our myFace Stars, an awards ceremony, and a benefit for the craniofacial community at our annual **myFace Celebrates** event

Further information is available on the myFace website



SAVE THE DATE

myFace
Celebrates...

A JOURNEY OF HOPE
PAST. PRESENT. FUTURE.

WEDNESDAY, JUNE 5, 2024
6:30-9:30PM
583 PARK AVENUE, NYC

Join us as we honor the legacy, embrace the present and unveil a vision for an ambitious future.

Upcoming Events at myFace

Join us for the next webinar in our *Transforming Lives Webinar Series*:

Considerations for the Diagnosis and Management of Children with Craniofacial Microsomia – Summer 2024



Carrie L. Heike, MD, MS

Associate Professor, Dept. of Pediatrics
University of Washington School of Medicine
Co-Principal Investigator
CARE Study
Pediatrician
Seattle Children's Hospital



Craig Birgfeld, MD

Associate Professor, Dept. of Plastic Surgery
University of Washington School of Medicine
Craniofacial Surgeon
Seattle Children's Craniofacial Center

Further information about this webinar will be available soon on the myFace website

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WEBINAR SERIES





Thank You for Joining Us!
We hope you enjoyed the program.