

Transforming LIVES

SUMMER
2023



Letter from Ken Salyer, Jr.: *Board Chair*

Dear Friend of WorldCF,

I can never thank you enough for caring so deeply about vulnerable children born with craniofacial challenges.

They often need multiple surgeries that take place over many years. Getting the proper care requires a huge investment of time, travel, medical expertise, and funding.

Your generous commitment means WorldCF can stand by children like Wafiq, Ace, Patricia, and Somto every step of the way.

I'm so excited for you to read the latest updates about these beautiful children. They've all undergone several life-changing surgeries that wouldn't have been possible without you!

You connect children to world-class medical care, from surgeries to follow-ups. And you help cover travel costs so a child in need doesn't have to endure a hard, lonely life with a devastating facial anomaly simply because of where they were born.

Thanks to you, WorldCF is increasing the number of patients who receive treatment. You're helping us identify partnerships with other like-minded NGOs. And you're supporting continuing education, fellowships, and scholarships to grow the number of medical professionals worldwide who can treat children with complex craniofacial conditions.

For a parent like Max, your support throughout their child's healing journey means everything. His son, Ace, will have his fifth surgery later this year. *"The doctors are the heroes, but the people behind the scenes are the ones making everything happen,"* Max says.

Please enjoy the success stories inside this newsletter. And know that your support makes them possible!

Ken Salyer, Jr.
Board Chair



IN THIS ISSUE

- A new beginning for a baby from Bangladesh
- Ace's story: "He's more excited about life"
- A transformation nine years in the making
- Thanks to you, Somto can breathe more easily



STANDING BY KIDS FOR THE LONG HAUL **Checking in on Ace**

Ace is still a few months away from his next surgery, but he's already thriving as a result of his previous procedures.

"He's able to talk more," says his dad, Max. *"He's more excited about life."*

Ace, now 5, was born with a Tessier facial cleft that extended from his cleft lip up to his left eye. With your help, WorldCF is ensuring Ace gets all the surgeries he needs to live his very best possible life. Last summer, doctors used some of the bone from his thigh to fill in where bone was missing in his face. They also transferred fat to fill in his left cheek.

"WorldCF has done everything humanly possible to get Ace the best treatment," Max says. *"They went above and beyond. It's a real blessing."*

In August, Dr. Chris Gordon — a WorldCF Medical Director and Head of the Craniofacial Program at Shriners Children's Hospital in Dayton, Ohio — will perform surgery on Ace to "level out" his left eye. After that, Ace will need additional surgeries to account for changes to his face and head related to normal childhood growth.

Through your continued support, you'll make sure WorldCF can be there for Ace and his family for as long as they need us — no matter what!

Ace is an outgoing, bright little boy who is quick to comfort others when they are sick or hurting. "Even though he looks a little different, everybody else has some kind of pain," says Ace's dad, Max. "He can sense that."

You Help Provide 'Mind-Blowing' Care for Kids

She's not yet a year old, but Wafiqah has already traveled from her home in Bangladesh to Dayton, Ohio, and undergone surgery to repair a severe bilateral facial cleft. It's been a lot for her mother, Watifa, to manage, but she knows the best is yet to come for her little girl.

"We are hoping for a better future for her and to give her a comfortable life," Watifa says. *"That is our main goal — a comfortable and smooth journey of her life."*

Wafiqah's surgery was performed in March by Dr. Scott J. Rapp, a cleft surgery expert, who repaired her cleft lip and facial cleft. In September, she'll have another surgery to fix her cleft palate. That surgery might also include work on her right eyelid.

Doctors don't yet know if Wafiqah will have sight in her right eye. But for now, she's eating well and has mastered the art of loudly letting her mom and dad know when she wants something. It's a huge relief to Watifa, who says: *"WorldCF and Shriners are just mind-blowing."*



"She's really doing fine now," says Wafiqah's mom, Watifa. *"Her situation was so severe, but the surgery was so good."*

Patricia's Healing Journey Continues

After nine long years, Patricia is now breathing free and easy — and it's because of supporters like you!

As we explained in our last newsletter, Patricia was born with Crouzon Syndrome and suffered from an airway obstruction that made it hard for her to breathe. In 2002, a tracheotomy allowed her to breathe through her throat. But doctors knew that wouldn't be a permanent solution due to the risk of infection and scarring.

So, in February, Patricia and her father, Patrick, flew from their home in Nigeria to Chennai, India, where Dr. S.M. Balaji successfully closed the tracheotomy. After the procedure, Patricia had to learn how to breathe through her nose and mouth. She also had to relearn how to eat and drink. She is now back at home, enjoying her new life.

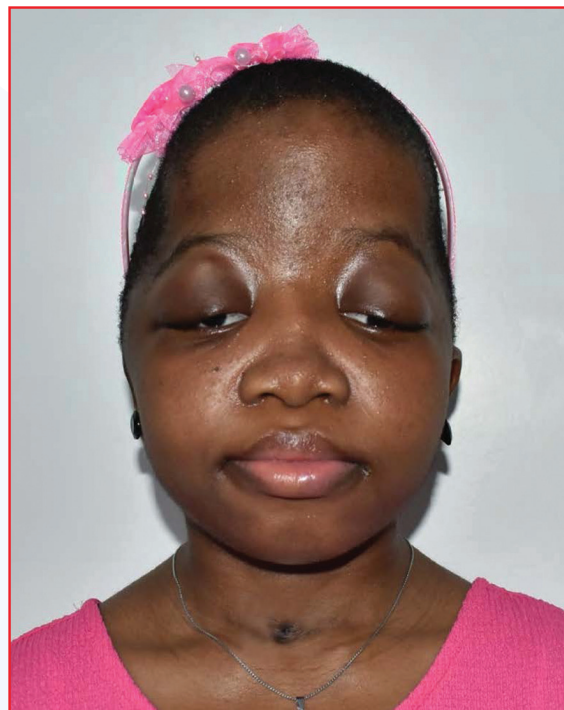
With your support, children like Patricia and their parents can focus on healing and moving forward.

“You can only imagine the joy and smiles in my family when the tracheotomy was removed,” Patrick says. “My daughter can now bite and breathe with her nose like everyone. All this was made possible because we found favor in [WorldCF].”

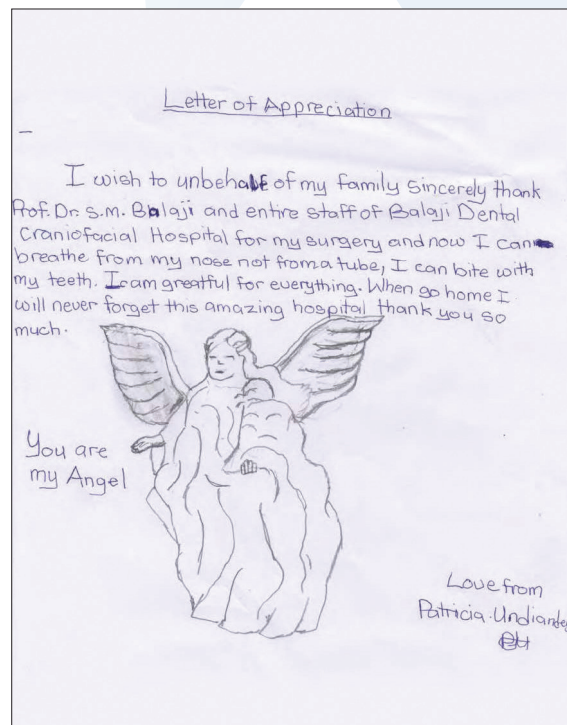
Your generosity makes it possible for patients like Patricia to travel thousands of miles to get the care they need. Without your help, most would never be able to afford the airfare and hotel stays, much less the medical treatment itself.

WorldCF facilitates free procedures from leading experts in craniofacial reconstruction. We help patients access pre-surgical testing and consultations, and we coordinate and pay for patients and their caregivers to travel, giving these families one less thing to worry about. With your support, children like Patricia and their parents can focus on healing and moving forward.

“Patricia was always positive, willing to take the challenge and learn,” Dr. Balaji says. “She enjoyed every minute of life and transformation. She was such a darling.”



Patricia, 11, had to learn how to breathe through her nose and mouth after having her tracheotomy closed.



Always upbeat and grateful, Patricia sent this sweet note of appreciation to Dr. Balaji and his incredible team in India.

UPDATE: The Next Steps for Somto

In our winter newsletter, you learned about Somto, a boy from Nigeria who, with your support, underwent a monobloc procedure, a type of osteotomy in which the bones are cut and repositioned. Somto's whole skull was moved forward to reshape his head and face.

In February, Somto traveled to Dayton for a second osteotomy performed by Dr. Gordon to treat obstructive sleep apnea. Sleep apnea is particularly dangerous for children. Because they cannot sleep properly, they can develop behavioral problems, struggle in school, be hyperactive, and experience poor weight gain.

Even more recently, Dr. Gordon performed work on Somto's posterior cranial vault — which makes room in the back of his head for his brain to grow normally. Somto will return to Dayton in the late summer or early fall to have his face and jaws corrected. This surely will not be the last time you read about Somto's journey, and we are feeling tremendously optimistic about the boy's future.

For now, Somto can sleep much better at night. That means he can wake up to brighter, more hopeful days ahead.



Somto is all smiles with Dr. Chris Gordon and his father, Tony, after his most recent procedure.



Supporters like you helped make Somto's first surgery possible in 2019.



These patients and their parents are becoming like family. (Back row, left to right: Somto's dad, Tony; Rony, holding his daughter, Wafiq; Arshad, Mujeeba's dad. Front row, left to right: Renee Johnson, RN-CM; Somto, Mujeeba; Julia McBride, RN-BSN)

JUST LIKE FAMILY

This past April, a few of our patients, their parents, and Shriners nurses gathered at the hospital in Dayton for some very special group photo opportunities. These patients and their dads have truly bonded over their time here in the United States, and have even been known to share a big meal together — just like family!

A sweet moment between patients you have helped!



Giving us stock can often be more beneficial than giving cash. You can completely avoid paying any tax on the stock's increased value AND you will be entitled to a charitable income tax deduction for the stock's full market value.

If you are considering a gift of stock, please call or email our Board Chair, Ken Salyer, Jr., so he can provide you with our stock transfer instructions. Reach him by email at ken.salyer.jr@worldcf.org, call him directly at +1.214.244.5237, or leave a message at +1.972.566.6669 or +1.800.533.3315 toll-free from anywhere in the U.S.



Please remember WorldCF in your estate planning and help needy children for decades to come!

World Craniofacial Foundation

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