



Lancaster Cleft Palate Clinic

SUMMER NEWSLETTER 2019

**A BRIGHT
FUTURE**



A BRIGHT FUTURE OF HOPE

What makes kids persevere through a touch dental appointment? How does a child cope when surgical recovery is painful? Why does a mom drive two hours—each way—to Lancaster every other month?

It's because they have hope. Hope is what allows us to persevere: the hope for a brighter future. It isn't fear that motivates us, or even worry. We dream of a brighter tomorrow. Each patient and family who comes to Lancaster Cleft Palate Clinic is part of that hopeful vision of a brighter future.

As you read in this newsletter about our friend Kylie, about an exciting new research initiative, and about some of our wonderful leaders, we want you to get excited for the progress we are making together. We also want you to understand that these journeys are not easy. Typically it takes 20 years of treatment per patient in order to achieve a successful outcome. The total cost often approaches \$400,000. It is because of the challenges, because of the hurdles, because of the difficulty of the journey, that we are so proud of the perseverance our patients display. They keep working when it's difficult, try again when they fail, and wake up each morning pursuing hard their hope for a brighter future.

Thank you for your partnership. We are eager to share these journeys with you!

With hope,

A handwritten signature in cursive script that reads "Elizabeth K. Prada".

Dr. Liz Prada
Executive Director

THE GIRL WITH THE BRIGHT SMILE

KYLIE'S STORY



“Lancaster Cleft Palate Clinic has walked with us hand in hand through a very difficult and transitional time in our family,” said Kris Kauffman, reflecting on the role that LCPC has played in her family’s life – and more importantly, in the life of her daughter, Kylie.

Lee and Kris Kauffman decided to adopt in 2014. They received a file for a beautiful little girl from China with an infectious smile in 2015, and Kylie joined their family in October 2015. In addition to undergoing open heart surgery prior to the adoption, Kylie had also undergone surgery to correct a cleft palate while in China.

When the Kauffmans realized that Kylie was not speaking clearly at age six, they decided to begin speech therapy with LCPC.

“(LCPC) has been absolutely, over-the-top amazing,” said Kris. LCPC has performed a minor surgery for Kylie, who is now nine, and currently, LCPC assists with orthodontics.

Kris praised the staff of LCPC, who have treated Kylie with compassion and kindness over the years. Kris recalled

one incident in particular when, after Kylie had a mishap and needed emergency attention, one doctor made room in her busy schedule to see Kylie and made her a priority.

“The doctors are sacrificing,” said Kris. “They are caring for different clients, and it’s a mission to these doctors.”

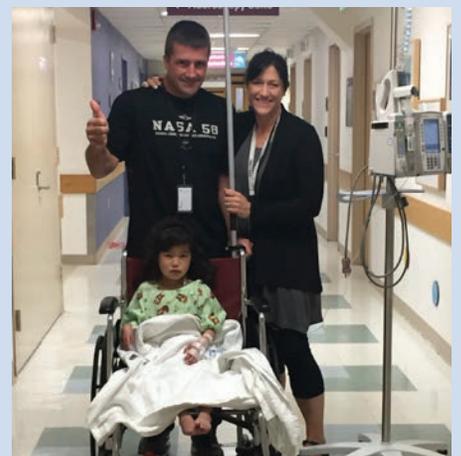
While some kids may be intimidated to visit the doctor, Kylie loves being independent and asks Kris to drop her off at the corner so she can walk in first by herself. Kris deeply appreciates how welcoming and kind the doctors are towards her daughter – which has put Kylie at ease over the years!

LCPC has provided Kylie with opportunities to heal, progress, and flourish.

“Our dream is for Kylie to be independent and give to society,” said Kris. “She has a delightful, sunny personality and we want her to focus on what she can do, and not what she can’t do.”



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EMBODYING THE SPIRIT OF CARE



*Dr. Manny Lamichane, Dr. Sarah Wentzel,
Dr. Kristin Connors and Dr. Tim Synder, partner in LOA.*

“You can’t learn or be trained in what Dr. Manny has,” shares Dr. Rusty Long about Dr. Manish Lamichane known as ‘Dr. Manny.’

‘**H**e has enthusiasm, intellectual curiosity, and the heart to want to be able to help,” Rusty said. “Without people like Manny doing what he does, that kind of generosity, we wouldn’t be able to provide services as we do. What Manny is doing is a result of the kind of person that he is,” he adds.

Initially, Dr. Manny came in to the clinic from private practice at what was then Long Orthodontic Associates (now Lancaster Orthodontic Associates or LOA).

“My decision to specialize in orthodontics was actually driven by my interest in cleft and craniofacial needs,” Dr. Manny

shares. “I love providing beautiful smiles for everybody, but there’s something special about providing that level of normality to kids born with facial differences,” he adds.

Doing his dental residency at Harvard allowed Dr. Manny to train at Boston Children’s Hospital, which he says is a leader in care. However, he notes, “The patients we see at Lancaster Cleft Palate Clinic, with the variety and extent of genetic syndromes, is the evidence that this clinic is on par with the leading children’s hospitals. It truly is the best kept secret.”

It’s clear that employees stay with LCPC because they love building bright futures for their patients and making a difference in the world, Dr. Manny says adding, “We get more out of the relationships. Healthcare providers want to help all their patients, but we do get more satisfaction out of caring for patients that we are uniquely able to care for, that no one else has the skills or technology to help.”

Over the years, the Clinic has benefited from the generosity of Lancaster’s more than 200 dental professionals. Dr. Manny is committed to making sure that LCPC has orthodontic coverage! He has made two of his orthodontists, Dr. Sarah Wentzel and Dr. Kristin Connors, and assistant Jessica Kraybil, available to the LCPC and to help with the orthodontic care of our cranial facial patients. “Anybody who gets involved enjoys the reciprocal benefit of knowing that they are putting the time, talent and treasure they give to good use,” Dr. Manny says. “It all goes to the patients, ultimately.”

As a parent himself, Dr. Manny feels connected to the parents of the Clinic’s patients. “I think about how stressed out I can feel as a parent sometimes, and I remember seeing one couple in particular, who made it look easy. They had fostered and adopted children specifically with craniofacial abnormalities, so we knew for a fact that their journey was never easy. But this mom and dad were pleasant, caring and loving. They really embodied the spirit we strive to attain in caring for our patients, as well.”





BE OUR BRIGHT SPOT

GIVE YOUR TIME, TALENT, AND TREASURE

YOUR GENEROSITY BRIGHTENS EACH DAY

We are so grateful for the support of our faithful donors. Because of those generous gifts, we can continue to provide help and service to those in need.

Lancaster Cleft Palate Clinic (LCPC) has brought hope and healing to children and families by providing bright, healthy futures for patients. As the fiscal year ends on December 31, 2019, please consider donating to LCPC in order to take advantage of an exciting opportunity, thanks to the Stabler Foundation.

LCPC has received the Donald B. and Dorothy Stabler Foundation \$100,000 matching grant, and our matching grant, as of the printing of this newsletter, is \$46,000. Every dollar that you donate will be matched, dollar for dollar.

Your gift helps families afford the cost of treatment and closes the gap between what families are capable of paying and what insurance might cover for treatment.

Help us end the fiscal year well, and more importantly, help us to continue creating bright smiles and bright futures for our patients.

THANK YOU FOR YOUR GENEROUS SUPPORT!

Lancaster Cleft Palate Clinic needs the support of the community in order to fulfill its mission to improve the quality of life for those with craniofacial conditions resulting from birth defects, trauma and disease.

It is easy to see what we value, based on how we spend our money. We tend to treasure the items or the causes that we contribute to financially. Since we treasure our money, we should seek to donate to worthy causes that benefit members of the community and even the world. LCPC does just that by providing healing and help to those in need. Give of your treasure – to support an organization that deeply treasures the betterment of quality of life.

Providers can also help support the mission of LCPC by giving of their time and talents. LCPC benefits greatly from gift-in-kind agreements with private practices and from the talents of people who are willing to give up their time. Rusty Long believes that fulfillment in a workplace is a powerful motivator, more so even than money. Providers can provide the opportunity for the staff to serve at LCPC for the sheer purpose to see children's futures brightened.

If you desire to leave a lasting legacy, consider remembering LCPC in your estate plans. Your gift will help LCPC continue to improve the quality of life for those with craniofacial conditions and provide hope and healing for them.

A CAREER CREATING BRIGHT SMILES

FAREWELL AND THANK YOU, MAUREEN!



Thirty-four years ago, Maureen became part of the team at Lancaster Clef Palate Clinic. “It’s the most wonderful place to work,” she said. And she knew it from the first day she arrived.

Over the years, Maureen has developed relationships not only with the staff, but with the families of the patients as well, through her work as a speech pathologist with LCPC.

“I was the ‘go-to’ person for anybody who had a therapy patient they weren’t sure what to do with,” she reflected. Twice she has given lectures at the IU.

“I’ve never looked back,” she said of her decision to work at LCPC.

“We’re not just a team of colleagues,” said Maureen, of the staff at LCPC. “We’re also friends. We have the best people here, but we’ve shared in family deaths and family happiness. We’ve shared in each other’s fears and dreams.”

“People stay forever,” Maureen said fondly. “It gets into your skin. It gets into your blood.”

Maureen recalled one particular patient who touched her heart from over the years – a little girl adopted from China with a cleft palate. Maureen described the progress the girl made, up until the point that the child was ultimately

dismissed from speech therapy, due to her enormous improvement. Maureen loves to see children flourish and build bright, hopeful futures for themselves.

Maureen has helped hundreds of children throughout her career with LCPC. She loves bumping into kids she’s seen out in public and getting to witness how much they have grown and changed.

Her hope and dream for LCPC is that it always exists, and that it is always just as warm and caring and humble an environment as it is now. “We always try to do our mission – which is to help these kids smile,” said Maureen.

It was a hard decision to retire, but she is planning to put her free time to good use. She is anticipating volunteering at LCPC, spending time with her grandchildren, and traveling.

“Speech therapy was definitely my calling,” said Maureen. Over the last several months, Maureen has been closely training Pilar Tobin, one of the talented, newer members of LCPC’s staff, to take over this critical role.

Thank you, Maureen, for your dedication to helping children with the brightest smiles experience the brightest futures!

“WE ALWAYS TRY TO DO OUR MISSION – WHICH IS TO HELP THESE KIDS SMILE.”

STAFF SPOTLIGHT



Darla Miles has been an employee of Lancaster Cleft Palate Clinic for thirty years. She works as the financial coordinator, and oversees accounts payable, payroll, and finances.

“I’ve always enjoyed coming to work,” she said. She gets to interact with patients at times and she loves knowing that the financial programs that LCPC offers helps patients pay for the care that they need when they cannot afford it.

One of the best aspects of her job has been interacting with fellow staff members. “A lot of the employees have been here for a while,” she said. “It’s like a family... If I didn’t feel that way, I probably wouldn’t still be here.”

Darla is already considering coming back for a day or two a week to volunteer, even after she retires.



ANOTHER BRIGHT BOARD MEMBER

Dave Hanson serves as chairman of the board of Lancaster Cleft Palate Clinic. He believes that the mission of LCPC alone is compelling, but equally as compelling is the commitment of its people.

“(LCPC) has a global reputation,” said Dave. He described his involvement with LCPC as an opportunity to carry on a legacy that helped put Lancaster County on the map as having the nation’s first craniofacial team.

After being forced to deal with a difficult health issue in his own family during the early 2000s, Dave has experienced firsthand how comforting it is to have doctors who are knowledgeable and confident when it comes to planning out a course for treatment planning.

Dave praised the LCPC board for its diversity, and its passion for the organization. The core mission of the board is “taking care of the kids,” said Dave, and that is the commitment that binds the board members together in unity.

“This is as good as it gets in terms of community investment,” said Dave, in regards to the importance of donating to LCPC. “I can’t think of another organization to whom I could give or I would to get a greater bang for the buck in terms of money spent wisely and efficiently, and having an enormous impact on a lot of kids’ lives.”

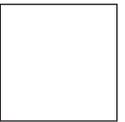
We are grateful that Dave’s service will continue in his ex officio capacity as our next board chair, Scott Fiori, President of Tristarr Staffing, assumes this critical leadership role.



BETTER RESEARCH, BETTER OUTCOMES, BRIGHTER SMILES

Lancaster Cleft Palate Clinic is pleased to be a leader involved in a new initiative: the Craniofacial Outcomes Research Network, or CORNET. This groundbreaking study will compare treatment options for children undergoing palate surgery at approximately one year and follow the results of their speech patterns for the next four years. CORNET is funded by the National Institute for Health (NIH) and has created a data registry for patient cases that will allow study to compare the results of various surgical and speech techniques.

Eighteen centers will participate in CORNET, including the five who have already begun. The participating groups have all agreed to standardize their records to enhance their comparative value. The benefit of CORNET is that it will yield *practice-based evidence* for speech and surgical procedures and protocols. The data registry will be stored for future generations. Dr. Rusty Long notes that participants look forward to learning from each other, and he believes that that with successful comparison for these speech and surgical outcomes, CORNET can be expanded to include other areas of craniofacial treatment research.



TAKE ME OUT TO THE BALLGAME!

Join us at 7:00pm on Friday, July 26 to celebrate National Cleft and Craniofacial Awareness Month at Lancaster Barnstormers, 650 N. Prince Street, Lancaster. \$4 for every ticket purchased will goback to LCPC!



Tickets can be purchased at groupmatics.events/event/LancasterCleft.

BIG STEPS TOWARD A BRIGHTER FUTURE

PATIENT MILESTONES

OUR PATIENTS AND THEIR FAMILIES MAKE US SMILE! We are proud of these key milestones reached by members of the LCPC family this year!

- **Abbi**, age 12, graduated from speech therapy in school.
- **Ava**, age 11, received a service dog.
- **Derek**, age 6, became fully potty-trained.
- **Erin**, age 20, has finished her sophomore year at Elizabethtown College and will have a summer internship as assistant stage manager at Gretna Theater.
- **Jordan**, age 1, took his first steps.
- **Logan**, age 18, committed to Albright College and will play soccer for them.
- **Kendall**, age 13, played middle school basketball, and played in middle school jazz band and concert band. She was asked to play in high school marching band despite being in middle school, and made high honor roll all three quarters of the year.
- **Molly**, age 11, came in first place with her science fair project.
- **Makenzie**, age 26, graduated from Rasmussen College with a B.A. in science in early childhood education and leadership with honors.
- **R.E.**, age 3, has learned how to ride a bike with training wheels.
- **Rowan**, age 1, met the Easter Bunny without any tears.



Ava and Baxter



Kendall



Logan



Molly



Makenzie



Rowan