



Lancaster Cleft Palate Clinic

SPRING NEWSLETTER 2020



**A JOURNEY
TO HOPE**



HOPE

IN UNCERTAIN TIMES

We are all experiencing unprecedented changes to our daily lives and society as a whole. During these challenging times, I urge you all to find hope in the moment. Find hope in the time spent with your family. Experience joy in the extra time spent in the sunshine. Experience the escape of reading that book that you have not had the time to finish until now.

I am finding hope in the clinic's future. As I write this, we are almost fully recovered from the flood that destroyed our lower level in October. The State of Pennsylvania has reimbursed our facility for damages, and for that we are extremely grateful. We would like to extend a particularly large "Thank You" to our elected officials, Representative Mike Sturla and Senator Scott Martin, for helping us to navigate the reimbursement process.

We are also finding hope in a larger renovation project that will transform our facility. We have been quietly soliciting support to improve our clinical spaces, add family-friendly amenities on "Team Day" and expand the services that we provide for our community. As we look forward to a less tumultuous time, we will share more details with you.

Until then, please stay healthy. There is no greater priority at the clinic than the well-being of our patients and staff.

With hope,

Liz Prada, DMD, MPH
Executive Director

HOPE MULTIPLIED

A CULTURE WITHIN A CULTURE: THE MAINS FAMILY STORY



Noah, Micah and Hannah

“LANCASTER CLEFT PALATE CLINIC HAS BEEN A LIFE SOURCE FOR US,” SAID RACHELLE MAINS – A MOM OF SIX.

The Mains have three biological children and three adopted children who range in ages from 14 to 5 – Olivia, Owen, Noah, Hannah, Grace, and Micah. The majority of them are patients of LCPC.

Noah was born with a partial cleft in the roof of his mouth, and when Rachelle found out a week after his birth, she was overwhelmed.

“I was beside myself,” she remembered, recounting how nurses instructed her on the proper way to give him a bottle, due to his condition. “I didn’t know how to deal with it.”

While Noah was still in the hospital, someone recommended LCPC to the Mains and provided the contact phone number. They brought Noah in for his preliminary visit within a few weeks of his discharge from the hospital.

His first surgery – the cleft repair – was performed when he was 13 months old, and Rachelle was relieved when all went according to plan. Noah, now 10, has just received his first round of orthodontics.

But Noah would not be their only child to benefit from the care of LCPC. The Mains always expected that adoption was not something they would pursue, but that all changed when one day, Rachelle says she heard the voice of God, urging her to “pray for a little girl.” Rachelle did just that.

When Rachelle and her husband had exhausted avenues for adoption in the U.S., they turned their attention to other countries, particularly China, where they found lots of children with clefts available for adoption.



The Mains Family

“We looked through thirteen files,” said Rachelle. “And we found her, in the last one. We just felt that she was our child.”

Little Hannah joined the Mains family soon after. In spite of her cleft lip, Rachelle said she is the happiest kid.

Dr. Samson performed her surgery and she healed well, and continues to demonstrate her resilience and her ability to overcome obstacles with an upbeat and sunny disposition.

The Mains will bring another adopted daughter, Grace, to LCPC. She had a facial cleft, which had been repaired in China, but Rachelle shared that they were concerned about how well the repair had been done.

Over the years, the Mains have gotten to befriend many patients and staff members at LCPC, thanks to their recent trips for care.

“We love that (the services) are all in one space, and everything can be done in one day,” shared Rachelle.

One of the most valuable aspects for the family has been the ability to connect with other families in the lobby of LCPC, especially families with other children that have been adopted from China. The Mains work to help their adopted children know and preserve their Chinese heritage, and have found that the LCPC relationships help them do just that.

“It really is a culture within a culture,” said Rachelle.

A HOPE FOR THE FUTURE

INTRODUCING DAVE FOULK, DEVELOPMENT DIRECTOR: A JOURNEY OF CARE

Dave is a Lancaster native and has worked in non-profit fundraising for several local organizations over 20+ years. Some years ago he stepped away for a while to focus on a real estate career, which he enjoyed. Then he heard about a fundraising position at the Lancaster Cleft Palate Clinic through his long-time membership in the Rotary Club of Lancaster—which shares a special relationship with the clinic: in 1938 Lancaster Rotary provided then-member, and clinic founder, Dr. H. K. Cooper, with funds to start the clinic.

“I’ll admit, I was intrigued,” Dave says with a smile. If you’ve ever met Dave, you will know him as a unique connector of people. He has spent much of his professional career building relationships with people and causes. It’s his specialty: the connection of a caring heart to the right cause.

Dave reached out to executive director, Liz Prada, and learned more about the development position, the on-going needs the clinic has, and discovered that the required duties were everything he had experience with. After a site tour he was on board.

Though Dave was familiar with the clinic, he feels as though it’s still one of the best-kept secrets in the region. He calls his work coordinating the fundraising for LCPC “rewarding.” “It’s important we expand fundraising beyond the local community,” says Dave. “It’s important we remind people we’re here, providing quality care for patients from throughout 45 counties in the state, and beyond.”

LCPC relies heavily on supporters of all kinds – individuals, businesses, and foundations – to make up 25% of the \$2 million annual operating budget. The clinic’s policy has always been, and remains, that no patient is ever turned away because of an inability to pay. To uphold this principle, donations are critical, especially considering that cranio-facial corrections can result in up to 20 years of healing for most patients and the procedures are not always covered by insurance.

“Donations from our supporters add up,” says Dave. “It makes magic happen here.”

Dave respects that the clinic is a family-friendly place, a place where people with similar conditions can come together to support each other. Supportive relationships and lifelong friendships develop between patients and staff members, making it a truly special place to be. “It’s not just about coming out of it with a nice smile,” says Dave, “but as a complete individual ready to take on the world.”



THANK YOU FOR YOUR GENEROSITY!

We rely heavily on our faithful donors to help us fulfill our promise never to turn away a patient because of an inability to pay for services. That is why we depend on contributions to make up 25% of our \$2 million annual operating budget.

Lancaster Cleft Palate Clinic has brought healing and hope to children for decades by helping them to achieve their full potentials and make strides to brighter futures.

We are committed to providing the best possible care for our patients and their families. Our donors enable us to uphold this mission and bring hope to the thousands of families that come through our doors each year.

Consider your part in helping us continue our mission of providing life-changing care by donating online today at

WELCOME

**RALPH MANNA, DMD,
GENERAL DENTIST**



Dr. Ralph Manna retired to something special. After operating two practices over the last several years and deciding to sell them, Dr. Manna knew he was going to retire to something related to dentistry. But the Harrisburg-based doctor hadn't decided what that would be. He had been familiar with LCPC for several years, and one thing led to another, and before long, he'd begun working one day a week at the clinic, providing general dentistry for patients.

Dr. Manna has been a dentist for 45 years and brings a wealth of experience to LCPC, where he sees a variety of patients, including older adults, teens, and those with special needs. He enjoys working at the clinic and participating in what he calls "a noble work."

"It's great fun," said Dr. Manna. "I'm delighted to help in any way possible."

Dr. Manna recounts how he bonded with an older patient who had an affinity for gaming computers.

"We bonded over his talent for computers and my stupidity about them," laughed Dr. Manna.

The patients are what give him such joy for his work.

"I would never miss the procedures," he said. "But I enjoy the patients. I would miss the patients. I am here because of the people."

BOARD MEMBER SPOTLIGHT

Scott Fiore, President, TriStarr | Lancaster Cleft Palate Clinic Board Chairman

Scott Fiore joined TriStarr in 1995 as a vice president of sales. He was named president in March 2019 and is in the midst of that transition process. Sales and marketing is Scott's skill set, but now he oversees all 15 employees and "has his fingers in all aspects of the company."

"I love to watch the market, see what changes are coming, working to react to the changes to improve the company, and watching my employees blossom," he said. Seeing his employees achieve and grow is one of his greatest joys at TriStarr. Another of his great joys has been his involvement with Lancaster Cleft Palate Clinic.

Scott was asked to join the board of LCPC about three years ago, during the time that Executive Director and orthodontist Dr. Rusty Long was considering his retirement. Scott enjoys helping non-profits and was excited that the mission of LCPC was something he could personally promote. He has a daughter who has a very rare, mild cranio-facial syndrome. She's been through five or six surgeries and still has minor cosmetic issues.

"I wanted to serve on a board where I could give back," he said. "I wanted it to be meaningful."

Scott is excited by the prospect of how the clinic can continue to grow and flourish in the midst of renovations and the capital campaign. The renovations are actually one of his biggest inspirations for continuing to serve on the board. He is also passionate about setting up the appropriate governances and structures to continue carrying out the current LCPC vision well into the future – a vision that he views of the utmost importance: continuing to make a difference in the lives of children.

Scott describes one of the powerful events he's witnessed at LCPC – comparing the very first photo kids have snapped of them at Team Day, compared to their final photo years later, when all of the progress and healing is clearly evident. Seeing their smiles is particularly special to Scott, since he's undergone a similar journey with his own daughter.

"I don't think there's an organization around that has a better return on investment," said Scott. "You can physically see the change that a donation makes in children's lives."



CREATING HOPE AND HEARING IN AUDIOLOGY



Over the last eighteen months, Lancaster Cleft Palate Clinic expanded services in our audiology department. Thanks to a donor's generous donation, we've added two technologies: Audioscan Verifit2 real-ear system and Vivosonic Integrity auditory evoked potential system.

Audioscan Verifit measures if a patient's hearing aid is meeting prescribed targets. Vivosonic auditory evoked potential system measures thresholds using surface electrodes. This technology - auditory brainstem response (ABR) testing - is particularly useful for infants and patients unable to respond to traditional behavioral hearing tests. It is the same testing used in hospitals for newborn hearing screenings.

According to Rachel Sharnetzka, AuD, CCC-A, these technologies fill voids in accessibility to pediatric audiology services in Lancaster County. We offer audiological services to patients regardless of age, which includes newborn hearing screenings, testing following failed screenings, occupational

hearing monitoring, comprehensive hearing evaluation, and hearing aid fittings. We hope including adults will improve upon what we provide to our pediatric population.

Rachel remembers a boy, adopted from China, who for the first seven years of his life, had hearing loss and a cleft palate. His adoptive parents brought him to LCPC where he was fit with hearing aids. "When I fit him, the smile on his face was priceless," said Rachel. Since then, he continues blossoming.



LIFE-CHANGING CLINICAL RESEARCH

Lancaster Cleft Palate Clinic is involved with clinical research furthering treatment and investigation, not only internally, but to share with patients and other providers.



Dr. Rusty Long, Director Emeritus and Research Director

OUTCOME DATA: Outcome data is used in house, and shared – protecting patient information – with other medical or dental programs. LCPC has been the source of data for almost 40 research studies of residents meeting research requirements. Outcome data helps LCPC improve treatment, and compare results from various approaches.

AMERICLEFT: For its 81-year legacy, the local team contributed to international cleft treatments. From the 1960s to '80s, a federal grant funded LCPC's study about long-term cleft treatment effects, like speech development, social adaptations, and hearing. Our archived data represents the largest repository of longitudinal data on treatment effects in children and impacts what we, and other practitioners, do daily. Following a push from the World Health Organization, the greatest impact is coming from a project we're leading called Americleft: a collaboration of specialists identifying the best treatments and management strategies, including a speech group, psycho-social group, surgical group, and pediatric/medical/dental group. We started with six member organizations, and now have over thirty. We're launching a five-year project to build an electronic registry of outcomes.

CORNET: LCPC is pleased to lead a new initiative: Craniofacial Outcomes Research Network (CORNET), which compares treatments for children undergoing palate surgery at approximately one year and follow results of speech patterns for the next four years. CORNET is funded by the National Institute for Health (NIH) and created a data registry for patient cases comparing results of surgical and speech techniques.

Eighteen centers will participate, including five who have begun. Groups agreed to standardize records to enhance comparative value. It will yield practice-based evidence for speech and surgical procedures and data will be stored for future generations. Dr. Rusty Long notes that participants anticipate learning from each other. He believes that with successful comparison for speech and surgical outcomes, CORNET can expand to include other areas of craniofacial treatment research.

JOURNEYS OF HOPE

SHARING OUR PATIENT MILESTONES

- **Molly**, age 12, started voice lessons.
- **Kyle**, age 6, presented to his class about his cleft lip/gum line.
- **Billy**, age 14, won first and second place at his horse show with Leg Up Farm.
- **Jordy**, age 6, started kindergarten and became a big brother again.
- **Ava**, age 6, played her first season of soccer with Lampeter-Strasburg Youth Soccer.
- **Miles**, age 6, was promoted to a new karate rank.
- **Kevin**, age 15, was accepted to the Rotary's short-term exchange program. He will spend three weeks in Switzerland in the summer.
- **August**, age 2, completed speech therapy (and got a new haircut!)
- **Cassandra**, age 28, got her CNA license.



Billy



Jordan



Miles



Cassandra



- FLOOD UPDATE - HOPE AHEAD

As you likely know, in October our lower level was flooded through an unfortunate accident of a broken water main resulting from PennDot street work in front of the Clinic. Everything touched by tainted water infiltration needed to be gutted—including furniture, file cabinets with decades worth of records and research, carpet, walls and mechanicals that run clinic equipment above. The cost for remediation has approached \$327,000. Some good news: the Commonwealth has agreed to reimburse us for the majority of this loss at \$250,000. The \$77,000 difference has definitely impacted our operating budget, so donations are always appreciated.

But some further good news: this set-back actually accelerated planned renovations to the overall facility through our Faces of Change capital campaign, which has been quietly unfolding for many months. So on your next visit to the clinic please don't be surprised to find lots of changes in progress. Renovations are planned in phases while we continue to remain open to our many patients and their families to provide services. Stay tuned for further updates as this exciting renovation unfolds and we look ahead to a public announcement about what's to come.





Lancaster Cleft Palate Clinic

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Consider your part in helping us continue our mission of providing life-changing care by donating online today at

OUR MISSION

The Lancaster Cleft Palate Clinic is a not-for-profit organization dedicated to improving the quality of life of infants, children, and adults through comprehensive coordinated treatment of craniofacial conditions resulting from birth defects, trauma, and disease.

NEW WEBSITE LAUNCHED!

We are thrilled to announce our new website:

Here, you can discover what a normal day at our clinic is like, learn about Team Day, meet our highly-accomplished team of professionals, hear from donors, and get better acquainted with our mission and vision for the future.

Here, you can discover



Donate online today at

FEATURES YOU WILL WANT TO CHECK OUT:

- Resources for various age groups
- “Beautiful Results” blog of our wonderful patient success stories
- Secure online giving for one-time or recurring gifts
- Updated team biographies and portraits
- Testimonials from our supporters explaining ‘why I give’ of time, talent or treasure