



Lancaster Cleft Palate Clinic

ANNUAL REPORT 2018



**BRIGHT SMILES.
BRIGHT FUTURE.**

80 YEARS: A GREAT BEGINNING



LOOKING TO A BRIGHT FUTURE



**80 YEARS HAS BEEN A
BRILLIANT BEGINNING**

Each morning, we see reflected in the mirror two prospects: the person we were yesterday, or the new person we could be today. Every day brings the opportunity for change, for growth, for a chance to impact the future.



At Lancaster Cleft Palate Clinic, *potential is realized* in the changing faces of our patients. *Opportunities are imagined* in the child whose newly enhanced smile is shared with one of our nurses. *Possibilities are evidenced* in the framed photos, side-by-side on a home's mantle, one showing a baby with a craniofacial abnormality, the other grown into a confident child. *Opportunities are heard* when a child in speech therapy produces a sound he'd never been able to form before.

Lancaster Cleft Palate Clinic is proud to be a part of watching families capitalize on the potential they already see in their child. In our eighty-year history, we have established an entirely new method of team care: the model that is now embraced world wide as the standard for cleft care.

At Lancaster Cleft Palate Clinic, the potential of the future is seen in the expansions and growth just on our horizon. As you read this annual report, you will be inspired at the new, life-changing technology we are implementing in various disciplines. You'll understand the need for expanded audiology and pediatric dentistry services to meet a great community need among special needs and disadvantaged children under age 6.

We are not without challenges. Key staff who have dedicated their lives to this cause are anticipating retirement. We have borne the huge hindrance of a leaky

roof and its expensive repair. We daily operate in tight quarters with a constantly increasing need for our specialty care. But this team buckles down, rolls with the punches, tightens our budget, and solves problems. That's who we are; that's what we do.

My vision is to maintain our independence while providing the highest quality of care with the best outcomes. How we do that will evolve, but we will also remain true to our principles: building educated care plans using outcome studies that weigh immediate and long-term results, allowing our patients to transform into the best versions of themselves. We help bring out the potential that mom and dad knew was there all along.

Eighty years has been a great beginning, but craniofacial needs are America's most common birth defect. As you look at yourself in the mirror tomorrow morning, you may not notice much change from yesterday. But today could be the day that everything changes for one child, thanks to our life-altering services. And by partnering with us, you, too, can change the faces and the possibilities for those in need.

With hope for the future,

Elizabeth Prada, DMD, MPH
Executive Director



A BRIGHT PROMISE

– by Angela Colasanti, parent

After a childhood accident, my husband faced a lifetime of breathing and eating challenges. We gained a profound understanding of the impact of proper medical care when a surgical procedure many years into adulthood finally allowed him to breathe through his nose for the first time. A two-hour procedure changed everything for him. I remember looking at him, with joyful tears in his eyes, and wondering, “IF APPROPRIATE MEDICAL CARE COULD CHANGE THIS FOR HIM, WHAT COULD THE BEST CARE DO FOR A CHILD?”

We had already begun the process of adoption when we asked our caseworker to match us with a child with a cleft. We met the LCPC team to ask what kind of need they were equipped to handle. What a poignant moment when the doctor's reply was, "You have to trust me, whatever it is—we can fix it. This team will take care of your child, whatever it takes."

A leap of faith matched us with our daughter, Qinny, and coming to LCPC turned out to be the single best decision we made for her care. We were at the clinic within a week of her homecoming. With a unilateral open palate, she grew up choking on everything she tried to eat and was resultingly malnourished. To top it off, thirteen of her twenty teeth needed fillings.

Over the next months and years, LCPC provided her dental care, performed a lip, nose, and palate repair, and additional surgeries, including a second palate procedure and reconstructive bone grafts. Maureen in speech therapy was Qinny's tireless champion, single-handedly helping our daughter learn to speak when the foreign sounds of English seemed to be an insurmountable challenge.

When I look back, Qinny was scared, timid, prone to hiding—normal things for a newly adopted child, but hugely complicated by her medical needs. Now, ten years later, thanks to specialized therapy for international adoptees and the transformative help of LCPC, she is a thoughtful, articulate, responsible, empathetic young woman. She runs track and loves science and engineering.

It's hard for any child to endure these treatments. Believe me, it's hard. But for Qinny, LCPC was a trusted resource in this lifelong process. This clinic offers children unconditional caring to realize their potential.



IN QINNY'S WORDS...

The clinic has always been kind and welcoming. The staff cares about me. I know they always have my best interest in mind. The Clinic has helped me to become the person I am today. While I am still in treatment, I have come so far, thanks to their help.



BRIGHT 2018 HIGHLIGHTS AND MILESTONES

AN 80-YEAR LEGACY AND ONLY A BEGINNING

For its entire 80-year legacy, this local team has substantially contributed to the international treatment of clefts. From the 1960s to the early 80s, a federal grant funded LCPC's study about long-term cleft treatment effects, such as speech development, social adaptations, hearing, and more. The data is still here in our archives, and it represents the largest repository of longitudinal data on treatment effects in children anywhere in the country. This data still informs treatment decisions and impacts what we, and other practitioners nationwide, do daily.

Today, following a push from the World Health Organization, the grandest impact is coming from a project we're leading called Americleft: a collaboration of specialists identifying the best treatments and management strategies. We started with six members, but now we're more than thirty. Soon, we're launching a five-year project to build a complete electronic data registry of outcomes.



Rusty Long,
DMD, MS,
PhD, Director
Emeritus

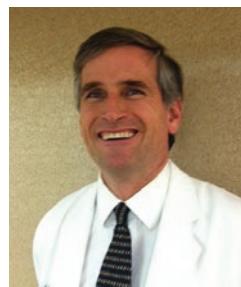
GROWING SPEECH AND NASAL ENDOSCOPY SERVICES

Lancaster Cleft Palate Clinic welcomes a new speech and language pathologist, **Pilar Tobin**, MS, CCC-SLP, to the team. Mrs. Tobin comes with enthusiasm and a passion for children along with a high level of skill and competency.

Speech therapy and surgery are often necessary treatments, but the endoscopic evaluations we can now offer, give the team a visual of the mouth, airway and nasal passages. Something as simple as a small camera inserted into your nose can bring a lot of new, valuable information! We make a video and present that at the team meeting to give the doctors even better information. Our team of professionals includes otolaryngologist **Bob Belser**, MD, and **Victor Da Costa**, MD.



Pilar Tobin, MS,
CCC-SLP, Speech
and Language
Pathologist



Bob Belser, MD,
Otolaryngologist



Victor Da Costa, MD,
Otolaryngologist,
fellowship trained
in Pediatric
Otolaryngology.



REACHING AN UNDER-SERVED COMMUNITY WITH AUDIOLOGY SERVICES

LCPC can now fit hearing aids and conduct newborn hearing tests with brainstem electrodes—no more referring patients away for these services! The timing for LCPC to add these capabilities is ideal as these services are difficult to access because demand exceeds appointment availability. We’re clearly meeting a community need when helping a child with chronic ear infections.

Most of our children qualify for medical assistance, so the services are paid for by the state. But the reality is that the clinicians serving this population aren’t paid well by the state, so very few private practices are able to continue offering the services, despite the huge need. Because we are a nonprofit and donor support closes that gap, we are able to fulfill our mission and serve the community in this way. I’m so blessed to be connected with these amazing, inspiring families. What they overcome is remarkable! Their positivity is rewarding.



*Rachel Sharnetzka,
AuD, CCC-A*

PROMISES FOR A BRIGHT FUTURE

\$540,953.07

**TOTAL
COMMUNITY
GIFTS**

**Your generous
gifts make dreams
come true.**

\$621,913.00

**UNREIMBURSED
CARE PROVIDED**

This number represents the difference in the cost to provide services, compared to the much lower reimbursement amount paid to us by government medical assistance.

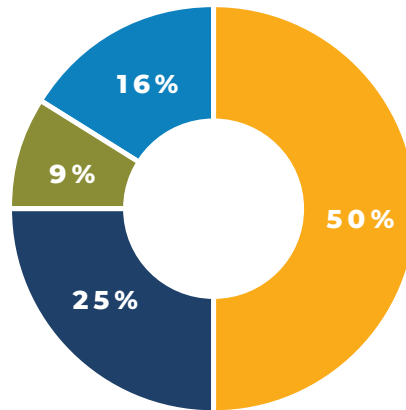
OVER \$44,000

**NON-REIMBURSABLE
EXPENSES**

This number represents cost we incur for which we cannot bill at all; for example a feeding specialist who goes to the patient's homes or hospital to assist the babies, or our social worker who provides psychosocial support.

NATIONWIDE UNDERSERVED PEDIATRIC DENTISTRY NEEDS

- Dental decay is **more common** in children who have a cleft as compared to those without a cleft.
- Dental caries is the most common chronic disease of childhood with 25% of children from **low-income families** entering kindergarten without ever having seen a dentist.¹
- Even when controlling for insurance status, **low-income and minority children** remain **less likely** than their peers to receive preventive dental care.²
- More than 25% of children **have tooth decay** in baby teeth before entering kindergarten.³



INCOME SOURCES

- Insurance/Self Pay
- Government Funding
- Research Grants
- Grants and Fundraising

**NEW
CRANIOFACIAL
PATIENTS**

71

**TOTAL
PATIENTS**

4,745

LCPC's cost to rehabilitate
one patient's cleft

\$400,000

CLINIC STAFF

- **18** full-time
- **5** contract employees
- **4** part-time
- **6** volunteer physicians

¹ NIH | ² Pew Research | ³ NCSL



THANK YOU FOR GIVING THE GIFT OF BRIGHT HOPE

OUR SUPPORTERS MAKE
ALL THE DIFFERENCE



SUPPORTERS

JANUARY 1, 2018 - DECEMBER 31, 2018

\$100,000 AND ABOVE

The Donald B. and Dorothy L. Stabler Foundation

\$30,000 - \$99,000

Samuel N. Lombardo Foundation
Mark Weiss & Julianna Eshbach

\$10,000 - \$29,999

Ann Barshinger
CRELS Foundation
Four Seasons Produce Inc.
Kiwanis Club of Lititz Area
Reformed Mennonite Church
William and Gemima Brossman Charitable Foundation

\$2,000 - \$9,999

Anonymous (2)
Anonymous ExtraGive 2018
Mary Baer
Brian Barna
Bunnie Buckwalter
Victor Da Costa and Liz Prada
Travis and Rebecca Finkenbinder
Philip and Patricia Frey
William and Kit Gamber
Gamber Foundation
Glatfelter Insurance Group

The Jack Buncher Foundation
Livingston Trout and Mellinger Medical Research Fund
Sidney Long
North Star Marketing, Inc
The Robert J. Bauer Family Foundation
The Robert J. Gunterberg Charitable Foundation
Rotary Club of Lancaster
Rotary Club of Lititz
John and Grace Rosenow
Tom and Georgina Russo
St. Thomas Episcopal Church
Brienne and Joel Taylor

\$500 - \$1,999

William and Susan Adams
Allen Family Foundation
Anonymous (2)
Anonymous ExtraGive 2018
Philip Bonanno





I've been blessed with four healthy children, and I've never had to go through a life-changing situation like the parents at our clinic. **I give and volunteer because LCPC is making a difference** in the lives of many, many children in South Central Pennsylvania. The professionals know the impact they can have, and that's why they're open with their extensive research: **so everyone, anywhere can grow and achieve their best potential.**

– *Bonnie Buckwalter, LCPC Board Member*

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 Dela Ches Fishing Association
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 Woodcrest Villa
 Jesse and Sarah Woodrow
 Harry and Carol Yost

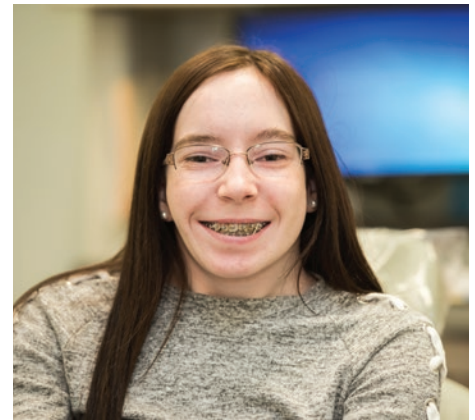
\$499 AND BELOW

James Alton
 AmazonSmile Foundation
 Anonymous
 Anonymous Exelon
 Anonymous ExtraGive 2018
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 Kevin and Missy Anderson
 Maralyn Anderson
 Robert and Jo Andrews
 Carol Ann
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Alene Bash
 William and Laralee Bash
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 Jacob Beiler
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 The Benevity Community Danielle Bidus
 Jennifer and Corry Bilby
 Kristina and John Bilek
 Walter and Zoe Mary Bilski
 John and Diane Bingaman
 Damian and Patricia Birchess
 Josh and Carey Blantz
 Frederick Bloom
 Billy and Emily Boone
 Alan and Susan Borislow
 John and Joanne Bowman
 Susan Bowman
 Tina and Randy Bowman
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 Ellen Brinton
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 David and Connie Burkholder
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 Jennifer Conner
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 Wasna Dabbagh
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 Pete and Rachel Higgins
 Timothy Higgins
 Dale and Sadie High
 William and Mary Anne Hinkson
 Le Hinton
 Bruce Hirte
 William and Cheryl Hoerr
 John and Dai Ann Hook
 Elizabeth Hooper
 Susan and Raymond Horan
 Zoe Horan



The Lititz Chocolate Walk benefits LCPC and 16 other community organizations that directly impact our local neighborhoods. This event is truly a community fundraiser: 4,000 pounds of raw chocolate is donated by a local company, 30 to 35 chocolatiers donate over 2,000 delicious and beautiful treats, and more than 2,000 tickets are purchased by engaged community members who believe in these causes. I've been honored to hear the stories of the way LCPC has changed the lives of children and their families, and it is this impact that drives our passion to support this team financially.

– **Allen Stoeckle**, *President, Kiwanis Club of the Lititz Area*

Jack and Mary Hostetter
 Grace House
 James and Alace Humphreville
 Patricia Huse
 Willem and Thea van Huystee
 IBM Employee Services Center
 IBM Retiree Charitable Contribution
 Impact Fund
 Isaac's Deli
 Kathy and Frank Jablonski
 Leonard Karpinski
 Grant Keener
 Megan Ryan-Keller
 Sue and Mike Kennedy
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 Anthony and Kathleen Kilkuskie
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 Kerry Meyers
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 Harry and Pamela Middleton
 Darla Miles
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 Scott Miller
 Amy Minoski



Bethany Leister
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 Mark Lewis
 Sam Lewis
 Christopher Lilley
 Sharon Lilley
 Christine Lindeman
 William and Joy Linton

Nancy Minoski
 Donald Main and Stacie Molnar-Main
 Michael and Lydia Morgan
 Arthur Morris
 Hadyn Morris
 Deirdre and Joseph Moyer
 David Peck and Cordelia Moyses
 Damien and Laura Mscisz

Our church supports LCPC's services for **economically disadvantaged and underserved children under age 6**. Our mission outreach committee matches the donations, which are usually around \$1,000. One year, our donations reached \$2,000. When we matched that, it doubled to \$4,000. But in the Lord's perfect timing, that was a year LCPC had been offered a matching grant. That \$2,000 from our church blossomed it into an \$8,000 donation!

– **Frank Fryburg**, *Head of Finance Committee, St. Thomas Episcopal Church*

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 Mt. Tabor Church of the Nazarene
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 Mary Yohe
 Susan Yourshaw
 Danielle Youtz
 Ronald and Marie Yurchak
 Gerald Zangari
 Ashley Zell
 Carol Zerbe

As a general dentist, I assumed that I understood all of the problems that could be associated with a cleft palate baby—until I had one. I realized that I had no idea the difficulties that cleft parents faced with feeding, speech therapy, ear tubes, growth and development, and surgical procedures. I am grateful every day for the extraordinary team at the Lancaster Cleft Palate Clinic. For years, they have guided my family through our son's extensive health and developmental needs. His individualized treatment and team care from the staff at LCPC have turned my 28-ounce micro preemie into a happy, playful, little boy. I couldn't be prouder of him!

*– From a clinic parent,
Melissa Crognale, DMD*



David Zobian





CAEL



LILLIAN



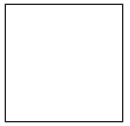
ELLA MAE



AMBAR



JORDAN



**BRIGHT SMILES.
BRIGHT FUTURE.**

**80 YEARS:
A GREAT BEGINNING**



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Entrepreneur (retired) Xerox, others

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.

