Why is Corey Smiling?

Wonder
A Must Read Book

Save the Date:
Winning Smiles
Family Golf Day
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Letter from Rusty

It's been a long, hard winter and we are especially grateful that Spring is just around the corner. We are also very grateful for the support we receive from all of you - whether in the form of financial aid, voluntary work or sharing our good news stories in the wider community.

We want to acknowledge Fig Magazine of Lancaster, which has selected the Lancaster Cleft Palate Clinic as one of their Social Mission Partners for 2015. Fig Magazine focuses on Lancaster City and every year they select several non-profits which they showcase throughout the year. We are fortunate to have been chosen by them, so look for their coverage of the Clinic throughout the year.

Our friends at the Park City Diner (Plaza Blvd) and Knight and Day Diner (Lititz Pike) have recently entered into a fundraising partnership with us. They will donate 10% of the cost of your meal to the Clinic. We appreciate their support, as well. To participate in this fundraiser see page 9.

Spring is a time of renewal and growth and we deeply appreciate all who are helping us move forward to make the Clinic a “home” for the children who come to us. As you’ll read in Corey’s story, the Clinic is a haven for kids who need our help.

Thank you all for your support.

Dr. Rusty Long

We are also grateful to:
Kae G. Wagner, President
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We are delighted to announce that the LCPC has been chosen by Fig Lancaster magazine as one of its three Social Mission Partners for 2015. To learn more about this honor go to our website: www.cleftclinic.org
Sheila Smith remembers vividly how she felt when her son, Corey, was born. “I felt so guilty because I didn’t know if his condition was because of something I had done. I felt overwhelmingly guilty.”

Corey was born with a cleft lip and a cleft palate and his mother, Sheila, was unprepared. “We didn’t have an ultrasound when I was pregnant,” she said, “so we didn’t know that this was going to happen. My main concern when he was born and we learned of his condition was ‘how was I going to feed this baby.’”

Like most new parents facing the challenges of craniofacial conditions, Sheila started looking for help. She worked with a nursing assistant at York Hospital, where Corey was born, and was very grateful for the experience the nursing assistant had with babies who needed special care.

“She told me about a Haberman feeder, so I was able to feed him and get some nourishment into him,” noted Sheila. “We went to the pharmacy to buy some of the Haberman feeders and they were getting ready to send them back to the manufacturer because they hadn’t sold any. So, we were lucky we got there when we did and were able to buy them.”

Dr. Davis, from the York Hospital, referred Sheila and Corey to the Lancaster Cleft Palate Clinic and Sheila was so grateful to find a place where Corey could get the special help he needed. Sheila remembers feeling so relieved to be at the Clinic. “As Corey grew older, he realized that there were other kids like

**Why is Corey Smiling?**

“What I want parents to know is that there is hope. They just need to reach out to the Clinic or to other parents and know that they are not alone.”
him. At the Clinic, he felt right at home.”

Corey had his first surgery at 3 months old to have his lip repaired. His second surgery came when he was 18 months old. In the second surgery, flaps of gum tissue from the part of his jaw that was not cleft, were used to close the hard palate and create a soft palate.

When Corey was 5 years old, Dr. Leber from the LCPC removed his tonsils and adenoids and attached the soft palate to the back of the throat. This was the first surgery that Corey remembers. Later surgeries included a bone graft taken from his hip to create a bone ridge for his teeth.

Corey notes that “no one judged me at school for how I looked. Kids would ask me about it and when I had the bone graft surgery from my hip, all the students made me cards.” Corey also had speech therapy and may need additional surgery for his nose in the next year or two. He’ll be getting braces in May, now that his new palate is in place and doing well.

As a teenager, Corey has experienced a lot more than his school peers. But, he has a “can do” attitude and is passionate about music. “I got a drum set for Christmas,” he said, “and I’d like to be a music teacher.” Other hobbies include fishing on the Susquehanna, going to the beach, playing video games (Skate 3 is his favorite) and skateboarding.

“The Lancaster Cleft Palate Clinic is absolutely wonderful,” Sheila says with a smile. “We are so happy to be there and it is wonderful for Corey to know that there are other kids with cleft as well.”

Sheila concludes with “what I want parents to know is that there is hope. They just need to reach out to the Clinic or to other parents and know that they are not alone.”

Corey was featured in our recent Promising Smiles Annual Appeal. To find out more and make a donation click on http://www.cleftclinic.org/how-can-i-help/donate/
Book Review

WONDER by R.J. Palacio

*** Suzanne Woodard has been the social worker at the Lancaster Cleft Palate Clinic since 2011. She works with children and families coping with cleft lip and palate and craniofacial differences at the Clinic. “It’s been almost two years since my then 5th grader came home from school and excitedly announced, “Hey mom, we are reading a really great book at school about a kid who has a cleft lip and palate.”

Really I thought? I was surprised, thrilled, and very curious. I quickly purchased the book and within a few days, I too was singing its praises to co-workers, friends, and family! And I’m not the only one. Wonder by R.J. Palacio has won accolades, awards, and been a #1 New York Times bestseller since it was published in 2012.

The book’s shining star is August a.k.a. Auggie, a 5th grade boy who is ordinary in every way, except that he has an extraordinary face. Auggie was born with severe craniofacial differences (including a cleft lip and palate) and has undergone over 27 surgeries in his short life. He has been homeschooled through fourth grade, but now his parents think it is time for a change. Auggie, however, is not so sure he feels ready to face the challenges of Beecher Prep! What follows is a beautifully written story about Auggie’s quest to navigate his new middle-school surroundings – to make friends, to stand up to bullies, and to learn the value of family and friendship. Telling the story from various characters’ perspectives, the author takes an honest look at the struggles we all face to “fit in.”

The reasons to pick up Wonder on your next trip to the bookstore are too many to list here. This is a book that offers readers of all ages new insight into ideas of friendship, acceptance, respect, kindness, and compassion. Enjoy and share Wonder with your children, grandchildren, parents, and friends.”

*** Elaine McClain-Rowe

“My name is Elaine Katherine McClain-Rowe. I turned 16 in December and have been a patient at LCPC since I was just a few months old. I love to read and am rarely found anywhere without a book. I also play viola and volunteer at my local library. And if that doesn’t prove that I’m a bookworm, I also co-founded a book club with my friend Sydney. In the future, I’m going to become a forensic scientist and travel the world. Thank you LCPC for all that you’ve done for me!”

“Wonder was an excellent representation of living with a craniofacial abnormality. Though Auggie, of course, had it worse than many of us LCPC patients do in order to create more conflict in the story, I thought it was extremely accurate. Palacio addressed many concerns that I myself have had, and I think she managed to portray these concerns without making the reader pity Auggie. I also enjoyed the change in point of view. In the case of many diseases and disorders, the focus is on the person who must endure it. Most fail to remember the
strain put on parents, siblings, and friends of these people. Wonder masterfully balanced Auggie’s perspective with those of his sister and friends. I would have liked to see the perspective of the parents as well. I particularly enjoyed sister Olivia’s perspective because it was so human. Older siblings can often be jealous of the younger ones because of the attention the younger child gets. But Olivia’s jealousy and inner conflict are even more understandable than most. Not only did she lose much of the attention she had, but it never balanced out between her and her brother as Auggie got older, because his health doesn’t allow for it. Perhaps she was selfish, but Olivia is one of the most honest, realistically human characters I have ever read about.

Wonder by R.J. Palacio excellently described life with a craniofacial abnormality, and those affected by someone with one. At no time did it feel like the author did not personally know of what she was writing. It was honest and sincere, serious and enjoyable. This book made me proud to be a cleft kid.”

*** Maria Sholly

Maria is 18 years old and a senior in high school. She enjoys taking care of her pets and playing the violin. Her parents are Jeff and Alisa and she has two brothers, Ben and Peter, and one sister, Hope. Maria plans to volunteer next year so she can decide what she wants to do in the future.

**Here is what she says about LCPC:** “The LCPC is amazing. Often when I tell people I was born with a cleft lip and palate they are very surprised. The only way I can prove it, strangely enough, is to show them my double uvula (the tissue which projects from the back of the soft palate). I didn’t always enjoy coming to the Clinic as a kid because it usually meant that when I got home I’d have some new apparatus in my mouth but that waiting room taught me to count my blessings because some individuals I met had to drive hours for a checkup or had to get major surgeries to fix their jaw which I never had to deal with. I’m so grateful for every appointment and surgery because there are so many children out there that don’t get near the same quality of care that I’ve received.”

**Here are her thoughts on Wonder:** “I really enjoyed reading this book. I especially liked the fact that every character had something they struggled with because everyone faces challenges in their life. Auggie had a craniofacial difference. Justin had tics. Olivia felt overlooked. Jack lost friends. Summer’s Dad died. Miranda’s parents were divorced. And Julian had nightmares.

I was very impressed by the author’s ability to write this book without having any children or close relatives dealing with a craniofacial difference. The whole experience of people looking at Auggie and then looking away quickly and staring at him when they think he is unaware of their gaze is so true. I’ve seen it happen plenty of times to people who look different. I’m glad that Palacio brought this out in the open. When people look different other people are going to notice. What is truly important is that we treat them with respect not just because we feel badly for them but because they are people too.

Telling the story from different perspectives was a unique style of writing which I enjoyed but at times the timeline of events was a little hard to follow.”

When asked if she could relate to Auggie’s experiences or feelings, Maria said, “Honestly nobody has ever treated me differently because of my appearance thanks to LCPC staff. However in some ways I could relate to Auggie’s sister Olivia because my brother is in a wheelchair and ever since I was young I never liked it when people stared at him.”
LCPC and Genetic Research

While a cleft lip or palate is the most common birth defect in the USA (1 in 575 births), parents and doctors have long speculated about the causes. Although the exact cause of clefting may be unknown, affected children are more likely to have a relative with a cleft than would be expected by chance. This suggests that genes may play a role in why clefts occur.

In the 1980s Mary Marazita, who holds a doctoral degree in genetics, began researching the cause of clefts. Recently the National Institute of Dental and Craniofacial Research awarded Dr. Marazita and her colleague, Dr. Seth Weinberg, at the Center for Craniofacial and Dental Genetics at the University of Pittsburgh School of Dental Medicine an $11.8 million grant, over 5 years, to undertake the largest study on the genetics of clefting ever done. The study will involve ongoing analysis of data from 12,000 participants plus the enrollment of about 8,000 new volunteers who will be patients with clefts, family members or unaffected volunteers. Family members are integral to the study as it is known that the same gene variants that cause clefting can have additional, less-obvious effects on dental and facial structure and function on related family members that could be predictive of the occurrence of a cleft. Participants will be drawn from Colombia, Nigeria, the Philippines, Pittsburgh and the Lancaster Cleft Palate Clinic.

The staff team at the Lancaster Cleft Palate Clinic is excited to be part of such a significant study. It is a mark of the high esteem for the Clinic in the medical research world that LCPC is a center for this research. Dr. Rusty Long, who is the principal investigator for this study at LCPC, said, “because of our reputation in this field, our long history of caring for patients with clefts, and our large population of families with one or more members affected by clefting, we were fortunate to have been asked to participate in this important study, being one of only two centers in the US to be involved. It would be incredibly helpful for generations to follow.

Interested in participating?

We are looking for unaffected parents, siblings or children of our patients with clefts who are at least 5 years old. Participation requires one 3-4 hour appointment. You will be compensated for your time and travel costs. For more information contact the Research Program Manager, Sue Scott, at 717 394-3793 or sscott@cleftclinic.org
LCPC and Genetic Research Article
continued from page 8...

come, to know more about the hereditary factors that put some families at greater risk for the occurrence of a cleft than others.” LCPC patients will start taking part in the study this year. While participants will receive no direct benefit from taking part, they will have the satisfaction of knowing that the information gained will lead to a better understanding of ways to prevent or reduce the risk of clefting in the future.

Looking for a new way to support the Clinic when you are in Lancaster?

Our friends at the Park City Diner (Plaza Blvd) and Knight and Day Diner (Lititz Pike) have recently entered into a fundraising partnership with us. Every time you pay for a meal at either of these diners they make a donation of 10% of your check to the Clinic. All you need to do is present a LCPC swipe card with your payment and they do the rest. If you would like a card, email your address to cmoyse@cleftclinic.org.
Winning Smiles Family Golf Day

Save the date!

Winning Smiles Family Golf

During these cold winter days we are beginning to fantasize about the summer, picking up our clubs and practicing our swing! Join friends of Lancaster Cleft Palate Clinic as we play mini-golf in the sun. This year for the first time we are offering two different venues on two different dates in June.

Sunday, June 14th
at Village Greens Miniature Golf
Strasburg, PA (near Lancaster)

Or

Sunday, June 28th
at Penn National Miniature Golf Course, Fayetteville, PA
(near Chambersburg)

For more information email cmoyse@cleftclinic.org.
Why We Give — Volunteers’ Expressions of Love

Meet two new members of the Winning Smiles Family Golf Day Planning Committee.

“It is an honor and privilege to volunteer at LCPC. I know from my own personal experience that cleft lips and palates involve a wide range of physical and psychological challenges. The professionals at LCPC are deeply committed to all aspects of patient care. The LCPC team’s commitment to their cause is truly inspiring, and I am excited to be a part of the LCPC community.”

— Mark Fetterman, Assistant District Attorney for Lancaster County

As with many great things in life, you sometimes don’t find them until you are in need. My daughter, Ryan, was born prematurely at 25 weeks in 2003. Weighing just a pound and a half, we got to know many of the great doctors, nurses, specialists and care givers in the Lancaster area. But it wasn’t until she was 8 and having trouble sleeping and breathing that we were introduced to the Lancaster Cleft Palate Clinic. She was diagnosed with Binder Syndrome which is a rare disorder that affects the upper jaw and nose. The team at LCPC was fabulous. They walked us through all the procedures that were going to take place and made us feel welcome and comfortable. Having this level of care and specialty in your very own community is priceless! Having experienced the LCPC team’s care for my daughter, Ryan, has been instrumental in my involvement with this year’s planning committee.”

— Erin Carr Gerhardt

IN MEMORIAM

We are very grateful for the gifts recently given in loving memory of:

Revd. Jonathan Currier
Olivia Grace Dusablon

Howard Eckhart DDS
Vincent Lattanzio
Dentistry that Makes a Difference

Lime Street Dental Associates is a private practice that offers a full range of comprehensive dentistry, orthodontics, and prosthodontics, with a unique distinction: all of the profits generated by their services go to patient care and treatment provided by the Lancaster Cleft Palate Clinic (LCPC).

“When you choose Lime Street Dental, you are doing something good for yourself and for the next generation,” said Dr. Andrea Smith, the Clinical Director.