

ccanetwork



newsletter of children's craniofacial association

2022: ISSUE 1

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Back Row From Left: Mary and Paul.
Front Row From Left: Will(6), Vincent(4), Desmond(2), and Bennett(8.)

meet the donatellis

by Mary Donatelli

Hello friends! My name is Mary Donatelli, my husband is Paul, and we are the parents of four incredible boys. We live in the San Francisco Bay Area and this is a bit about our journey with Apert syndrome. It starts when we were pregnant with our first son, Bennett, in 2013.

During our 20-week ultrasound, several "mysteries" were revealed about our little one. It was discovered that his fingers and toes were fused, and his head shape was different because of fused sutures. At one point in the pregnancy, he was thought to have a fatal heart condition. We spent the month after that ultrasound thinking our sweet baby wouldn't make it. We were devastated and it was a lot to process. Thankfully, a follow-up ultrasound revealed that his heart was just fine—apparently the first machine had a smudge on the lens.

see Donatellis, page 2

letter from the executive director



the beginning of spring is one of my favorite times of year. It seems like overnight the greenway in my neighborhood goes from a bare, gray walkway to an explosion of purple and yellow blooms, stalks as tall as my waist! I could swear just yesterday not a leaf was there. Vibrant green weeds, creeping vines, and blimpish bumblebees have suddenly taken over where nothing was just hours ago. While the mornings are darker, the birds are louder than ever. Were they here all along? Did they sing like this in the winter and I just missed them?

In a way, I feel like the eruption of spring is what...

see Letter from ED
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Can you believe that? Well, it felt like a miracle to us, and I always think of it as our first miracle with Bennett. We could not wait to meet this mystery guy!

Our team at **University of California San Francisco (UCSF)** didn't really know what to expect—they assumed perhaps he had Apert syndrome, but his prenatal genetic testing came back negative for Apert, so they were left scratching their heads a bit. None of us could say with certainty how things would go or what would happen when he was born. Regardless of who this little boy was, we loved him fully and completely. I was full of a "peace that surpassed understanding." I truly felt that everything would be okay, somehow, and I'm very grateful for that gift. We were so excited to meet our baby and ready to dive into all the things that lay ahead. We knew we needed a special name for him. We chose Bennett, which means "little blessed one," because he certainly seemed blessed to us. Little did we know WE were the ones who were blessed to have him as our son!

As you can see, the birth of our first child was very highly anticipated, and on a foggy San Francisco summer night at UCSF on July 30th, 2013, our precious son was born.

There were several teams of nurses and doctors in the room when he was born, and they were ready for every situation—all the teams ready to spring into action the moment he entered the world.



I will never forget looking over at the table when the team had whisked him away from me. I could see his little hand outstretched, fingers fused together in the sweetest mitten hand I could imagine. And then they handed him to me for the first time and he looked right in my eyes. He was breathing! He was amazing! It was pure magic and pure love.

Paul went with Bennett to the NICU where it was discovered that he had some digestive issues. His first surgery was just a few days later. In all, he stayed in the NICU for 2 weeks before we could finally bring him home.

We had a lot to learn about Apert



syndrome, and early on, he had many appointments with the craniofacial team at UCSF. We are so grateful for the kind introduction we had to Apert syndrome and to our craniofacial family. From the beginning, we were welcomed with open arms from others who had walked this same road, and it was so nice for us to connect with families who had been through the things we would soon go through as well.

When Bennett was 4 months old, he had his first skull surgery to open up the fused skull sutures and reshape the head so his brain would have room to grow. There was a slight complication and unfortunately, just one month later, he had to have another skull surgery and an extended hospital stay. His first two years included a lot of hospital time, endless appointments with different specialists, and lots of therapies and assessments. He had seven surgeries before he turned 3, including two of his four hand surgeries that were done at Stanford. During this time, we learned a lot! We learned how to spend days and sometimes weeks at the hospital post-op, how to

donatellis, continued from the cover

care and advocate for him, how to get to his appointments all around the city riding buses and trains, and really how to ENJOY the ride of raising our wonderful boy. He is the light of our lives and has always been so funny and joyful, even through his ups and downs.

We moved to the East Bay suburbs when Bennett was 2 (I just couldn't push his stroller up any more San Francisco hills!). We were also ready to grow our family and for Bennett to have siblings! We welcomed our second son, Will, in 2015, our third son Vincent, in 2017, and our fourth son, Desmond, in 2020. Life with our four boys is very entertaining, loud, and busy in all the best ways. They bring a lot of life and fun to this party of 6! We are also a homeschooling family, so we get lots of time to read, write, and learn about the world together.

Bennett is 8.5 years old now, and in the third grade. His passions are geography and soccer. We love learning about other countries and cultures together and Bennett loves to read atlases and study maps. He also plays soccer for several hours every day, either with his brothers, or outside by himself. His favorite team is Liverpool. My husband Paul, his brothers, and Bennett will wake up early on the weekends to watch the matches. He is joining his first soccer team this spring. He also loves zebras, the color red, and spaghetti with lots of parmesan cheese. Years ago, he invented something called "hug time". Every day at 5:55 pm, an alarm goes off on our phones

and we all stop what we are doing and hug each other. It is really sweet and every day at 5:55, and throughout the day really, I am reminded of his big heart and how grateful I am for all the gifts and creativity he brings to our family.

He and his brothers also love designing different sports and geography-related games and drawings for themselves. They keep themselves very busy with their imaginations and we are so grateful they all have each other. Bennett is good-natured, very adaptable, and also strong-willed and passionate about the things that are important to him.

As a family, we love reading together (currently going through the Harry Potter series), going on family adventures to the beach or to other Bay Area spots, and trying vegetarian foods from around the world.

Something we love about Bennett is that he is very determined to figure out how to do everything. He has the will and ALWAYS finds a way, even if it may look different from how something is typically done. His OT and I sat in amazement when he was 9 months old as he figured out how to open a peanut butter jar with no knuckles and unseparated fingers at the time. He simply turned the peanut butter jar on its side and used one hand to stabilize it, while using his other hand to rotate the lid. Our mouths

dropped when we saw it, and I have to say that Bennett is still doing this kind of thing to this day. We'll assume something will be tough, but he finds a way to show us that he knows JUST how to figure it out, on his own terms, in his own unique way, on his own timeframe. At one point he taught himself to use scissors by locking himself in his room with a stack of construction paper. About an hour later, he emerged triumphant with that same stack, now cut up in small pieces. His



donatellis, continued from the cover

creative problem-solving skills and his fierce determination are on display every single day.

Like many of you, we also deal with staring and rude comments. Bennett is learning how to stand up for himself at playgrounds or other public places. I have always dealt with the staring by waving enthusiastically at the person staring with a big smile on my face. I find that people will either quickly look away because we have broken their "trance" or they will say hi and smile too. It can become very frustrating as a parent to see your child go through this, but I know it is even harder for Bennett. He recently encountered a kid on the playground that was staring, and he went right up to him and confidently said, "Hi, I'm Bennett! What's your name?" My husband and I were so proud of him! We hope that he always has that confidence inside of him to just be who he is, and know that he is loved just as he is.



We try to respond to questions and comments with kindness, and do respond kindly most of the time. However, as I'm sure all of you know, sometimes you just don't have it in you to create a "learning experience" for the other person, or at least to do it with patience every single time. We are trying to teach our boys that we can't control what other people do or how they act— all we CAN control is what we put into the world, and hopefully that is kindness, compassion, and lots of love. That's all any of us can really control, you know?

Bennett wears hearing aids, and soon will be starting the orthodontics part of his craniofacial journey. Having had 15 surgeries total, (with more on the horizon, including the mid-face surgery), as he gets older, we try to have him advocate more for himself with doctors and different medical procedures. We try to be as transparent as possible with him about what is going on medically and try to empower him as much as we can. Being connected with the Apert community, as well as the craniofacial community in general, has been one of the biggest blessings on this journey. This community has been an absolute lifeline to us, always there to help us with a medical or personal question and there to offer support, friendship, and encouragement for the different things that come up.

We have also experienced incredible support and kindness from our family and friends throughout Bennett's whole life,



particularly during our many hospital stays. I will never forget the incredible visits and food deliveries to our hospital rooms from family and friends. I may have gained 20 pounds from all the deliciousness and stress eating (ha!), but that is a small price to pay for having our spirits lifted by people showing us love in this way. It really boosted our morale to eat something special at least once a day to get us through those long hospital days with our Baby Bennett.

Overall, people have been willing to learn alongside us what Bennett needs and how to support him. He has so many wonderful cousins and friends that have been there to cheer him on and we hope he always feels that love and can give it back to other people.

This will be our first year attending the CCA retreat and we are really looking forward to meeting some of you in person. So grateful for this community. Can't wait to meet you! 🧡





meet mason

my name is Mason. I'm six years old and I will be seven in August. I was born with Crouzon syndrome. I don't remember most of the surgeries I've had because I was so young, but I have some great doctors I visit regularly who help keep me healthy. I am now in kindergarten, and I look forward to going every day. I like to know how things work and I love learning. I'm generally a very good listener, unless I'm really focused on a project I want to finish or I'm hungry. Thankfully that doesn't happen very often in kindergarten because we have a schedule. I'm good at following schedules. I especially like the daily "specials" activities in kindergarten, which rotate between art, music, and physical education, with art being my favorite. I also like learning to read and seeing my friends at school. I am always excited for the weekend, too, when I get to do things with my family. (I've usually got my eye on the calendar, because I like knowing what month and day it is, and when different events are going to happen.)

When I'm not in school, I like spending my time drawing, building things, playing board games with my Dad, reading with my Mom, making up jokes, going on bike rides (with snacks), roughhousing with my sister Emelyn, and going to the playground. Sometimes kids on the playground who do not know me ask "why do your eyes look like that," which is annoying. I just tell them we are all different and I was born with special eyes. They usually understand after that, but not always. The kids at my school understand and are very nice, I really love school! My family and I are going to our first CCA Retreat this summer and we are looking forward to meeting new friends!



cca kid

ccasupersib

meet emelyn

emelyn is four years old and is quite the rambunctious little sister to Mason. She is so tall for her age, people often think the two of them are twins. Emelyn loves "playing roughhouse" with her brother, during which time she fills the house with her frenetic shrieks and giggles while Mom and Dad futilely remind them not to get too wild.

She also likes watching movies about princesses and anything to do with unicorns.



She occasionally does puzzles or board games with Mason, but that does not always go very well. Emelyn is more of a free spirit who does not see the point of following all the rules (plus it's much easier to win without them!).

Overall, Emelyn greatly prefers imaginative play and things that involve running, jumping or climbing. One of her favorite things of all is to ride



bikes with her brother. She is just as fast as he is. Emelyn looks up to Mason and is very proud of his new reading skills, and she likes the way he helps her with some of the things she cannot yet do on her own. When Mason has to spend the night at the hospital, Emelyn misses him very much and constantly asks, "when will he be home?" Mason and she always want to be together, even when they are bugging each other! They like coming up with fun ideas together, helping each other, and especially making each other laugh. Mason says she is a good little sister, at least most of the time! 🐣



letter from the ED, continued from the cover

emerging from our pandemic precautions is like. As we are planning our Annual Family Retreat and Educational Symposium, I am truly excited and thrilled to see our people coming together. Color and sound will overtake the Sheraton Dallas and a new energy will fill the air. As we anticipate this gathering, I am reminded that we are long overdue for a psychological refresh.

I was one of the most COVID cautious people I knew. My "bubble" and I literally spent 2.5
6 years running from this virus.

As many of you know, I experienced both immense joy and deep grief during this time, too. So much of those intense emotions were not able to be shared, celebrated, or mourned the way they deserved. Yet, I clung to hope and through my beloved CCA community, we found ways to still connect and buoy each other's spirits. We made do and held fast to the belief that good things were coming.

Then, just when it seemed like the path ahead was sunlit and blooming, I actually got COVID! The very thing I'd spent the

better part of over 20,000 hours avoiding showed up one afternoon as a fatigue-induced nap and stuck around for over two weeks. I was shocked ... in a way, I was relieved. I survived the boogeyman I'd been so afraid of! I didn't have to avoid people any more on the basis of germs. I didn't have to worry I was one unmasked conversation away from infecting my family (which I ultimately did). It was here, and now the thing was just to deal with it and recover.

But I was also so saddened. In the time we'd spent avoiding it, so many memories were not made.

letter from the ED , continued from page 6

Memories that I in particular will never be able to get the chance to make with loved ones. Does it mean I had made the wrong choice?

After much reflection, No, I don't think I made the wrong choice.

So many families have lost loved ones to this wily disease. Others are living with long-term negative effects. These people are also living in the shadow of "missed memories." But if you're feeling similarly... you have my permission to stop beating yourself up, too. We did the best we could with what we knew at the time. I'm always reminded of Maya Angelou's quotation,

"Do the best you can until you know better. Then when you know better, do better."

The better me – the me that became a wife, lost a sister, became a mother, and yes, survived COVID, knows that all life is cyclical. Just like my neighborhood greenway. The beautiful flowers that returned from nowhere were there all along, underground through the cold gray winter. And when they did make their return, they brought with them intense allergies, stinging wasps, annoying gnats, and even snakes in the tall grass, but they are beautiful and they make my heart light.

The better me knows that we are returning to activities as an

organization, and as weedy and snakey as our first attempts may be, they will lift our spirits and remind us that those deep, abiding bonds we share have been there all along and they are worth the work it takes to nurture and prune them.

Friends, it is time to celebrate one another again. Time to express our gratitude for surviving the dark times, to practice forgiveness for disagreements and differences when we were all being tested, and to remember that we are the hope we seek. Your phone call, text message, and in-person hug could be the brightest spot in someone's day. Do not withhold that love over a perceived difference of opinion.

I sincerely thank all of you who have been with me on this journey of the past year plus. Your support has been deeply felt and absolutely needed. Thank you for being my extended family – and I can't wait to welcome you back in Dallas this June!

- Erica Klauber
CCA's Executive Director

...
this issue of the E-Network is dedicated in memory of Erica's Sister, Emily Daisy Crabtree.



gingertown 2021 raises over \$30K for CCA Kids

by Christine Andler

The annual **Gingertown** is one of the biggest gingerbread house events in the US and all proceeds benefit **Children's Craniofacial Association**. Ginger-town brings together talent from more than 25 local design, engineering, and construction firms in Dallas/ Fort Worth for a live gingerbread building competition and exhibition to help spread joy and hope during the holidays at Dallas's premier shopping destination **NorthPark Center**. Millions of people nationally and internationally visit the Center



Christine Andler, CCA's Director of Development, Khadija Moten, CCA's Outreach Director, & Annie Reeves, CCA's Program Director

each year. We are so lucky to be one of their partner organizations. Having a live build in 2021 was a game time decision, but thankfully we were able to safely have the annual build and it was truly special. Due to the ongoing pandemic, the sponsorship opportunities were cut by a third and we were not sure we would raise as much as we had in past years. So when I finally heard the total raised, I was completely blown away! Our 2021 event raised just a bit over what our 2019 event raised, despite hosting only a third of the sponsors! We are so grateful for all those that came out to support CCA. Special thanks go to

especially **Brittany Denison** for speaking on behalf of CCA. It was truly a night of Joy!

In total, Gingertown raised: \$30,044.21!

We are so grateful for this loyal partnership with NorthPark Center, where they showcase our organization to the community in such an incredibly unique way. It was nothing short of amazing seeing this year's Gingertown fundraiser come back to life with the creation of Santa's Village Gingertown. It is one of the biggest local fundraisers for our small organization and it gives us the opportunity to support our incredible and resilient kids born with facial differences in a truly impactful way. Thank you from each of us at CCA!

- Christine Andler
CCA's Director of Development



legacy giving

Simply put, planned giving enables you to make a meaningful gift to CCA that reflects your beliefs and values. Your gift will create an enduring legacy by supporting CCA Kids during your lifetime and beyond. We are happy to help you choose the program or services that mean the most to you, as you make your estate plans.

To learn more about how to leave your mark on the world through supporting CCA Kids and Families, visit:

ccakids.org/legacy-planned-giving/
or email Christine at candler@ccakids.com

shane & courtney at depuy synthes

by Khadija Moten

CCA board member, Courtney Vysocky, and her son, Shane Vysocky presented their craniofacial journey at the DePuy Synthes CMF National Sales Meeting in Colorado Springs, CO on March 17th. The family spoke on behalf of Children's Craniofacial Association.

CCA has previously partnered on a virtual speaking session with DePuy Synthes in 2020 with our former board member, Russel Newman, and CCA teen, Nathaniel Newman. We were excited for yet another opportunity to speak with them, but this time in person!

Shane (also known by his social media moniker #superheroshane) shared his journey living with Crouzon syndrome and bilateral conductive hearing loss. He and Courtney shared pictures and reflections from his experience with the Rigid External Distraction and Internal Distractors devices. They shared Shane's experiences throughout his craniofacial surgical journey to 150+ medical device sales representatives and other

members at DePuy Synthes CMF. The event invigorated and inspired the sales teams to continue to provide unparalleled support to the top craniofacial surgeons in the world, deploying DPS CMF innovation to advance patient care.

The night prior DePuy Synthes hosted a fundraiser to raise funds for CCAKids and families.

We are so grateful for all of their efforts! 

DePuy Synthes is the orthopaedics company of Johnson & Johnson. They specialize in solutions for reconstructions, trauma, cranio-maxillofacial, spinal surgery, and sports medicine.

"We loved having Courtney and Shane (and Shane!) join us at our 2022 DePuy Synthes CMF National Sales Meeting this year. They were extremely brave, honest, and passionate. They are an inspiration to our salesforce for their resiliency through Shane's craniofacial journey. We would be lucky and honored to have them speak for us again in the future."

-Sophie G.

DePuy Synthes Associate Marketing Manager

Become a CCA Speakers' Bureau member!
For more info visit:
ccakids.org/speakers-bureau/
or email Khadija at: kmoten@ccakid.com



upcoming events

MAY 16th, 2022

Timarron Country Club Golf Course
| Southlake, TX

6TH ANNUAL PAR PREMIER GOLF
TOURNAMENT
BENEFITING CHILDREN'S
CRANIOFACIAL ASSOCIATION

CONTACT:

Christine Andler, candler@ccakids.com

MAY 21, 2022

Cascade Township Park | Grand
Rapids, MI
(3810 Thornapple River Dr. SE, Grand Rapids, MI 49546)

SPRING CRANIO PICNIC

CONTACT:

Tricia Brusk

Additional Details at:

<https://tinyurl.com/craniopicnic>

JUNE 23rd-26th, 2022

Sheraton Dallas Hotel | Dallas, TX
(400 N Olive St, Dallas, TX 75201)

32ND ANNUAL FAMILY RETREAT &
EDUCATIONAL SYMPOSIUM

CONTACT:

Annie Reeves, areeves@ccakids.com



SEPTEMBER 2022
Nationwide

18TH ANNUAL CRANIOFACIAL
ACCEPTANCE MONTH (CAM)

CONTACT:

Annie Reeves,
areeves@ccakids.com

SEPTEMBER 10, 2022

Dallas, TX | Details to come.

15TH ANNUAL DALLAS CAM PICNIC

CONTACT:

Annie Reeves, areeves@ccakids.com

Left to Right: Sophie G., Shane V., and Courtney V.



meet alexis

by Alexis Romero

hi, my name is **Alexis Romero**; I am 18 years old and was born with Apert syndrome. I've had 20+ surgeries throughout my life. Sometimes, it is challenging living with a craniofacial difference, but it doesn't bother me that much because I believe I am beautiful! Our differences are what make us unique. I embrace my beauty, and so should you! One of my favorite hobbies is creating music and playing my piano. As a child, I got inspired by a famous pianist and keyboard player, **Jeff Fatt**, who was part of "The Wiggles" band. I also enjoy listening to my favorite music artists, **Adam Levine**, **Nick Jonas**, and **Ed Sheeran**. They are fantastic pop singers, and my favorite songs are "Girls Like You," "Sucker," and "Photograph." I enjoy reading as well. My favorite books are: "Dork Diaries" series, all seven "Harry Potter" books, and the "Rush Revere" book series. I also like creating funny videos on TikTok

One thing I like to do for fun includes playing with my Nintendo Switch. Some of my favorite games are "Banjo Kazooie," "Animal Crossing," and "Zelda." Family movie nights are the best, too. I also like to go shopping with my family. Sometimes we go to the mall, and one of my favorite stores is **Hot Topic** because it has a lot of Harry Potter merchandise. I love spending time with my four dogs, as well. Their names are **Skitz**, **Chloe**, **Chico**, and **Dusty**. Other days I video chat with my friends. I hope to see them at this year's CCA Retreat.

Currently, I am a homeschooled high school senior. I look forward to graduating this year and plan to enjoy my summer with fun activities, like camp, and earning my driver's license! I plan to attend college in the fall and pursue a music career. I am excited to participate in this year's in-person CCA Retreat, reconnect with friends, have fun, and make new friends! 🥰



financial assistance testimonial

by Victoria Shay

Our son, James, was born with a rare genetic condition called **Treacher Collins syndrome (TCS)**. TCS exists on a spectrum and James is considered to have a mild case of TCS. He was born with a smaller jaw, malformed ears, hearing loss, and underdeveloped bone in his cheeks and jaw. James was diagnosed after he was born. Like so many parents before us, we experienced the overwhelming joy, love, and triumph of birth only to have it taken from us in a moment as our eyes landed on our son's face, knowing something was wrong. It's a moment you don't forget. It was that moment that catapulted onto this medical journey we are on now.

As I reflect on the first few months of James' life, I remember it as a



rollercoaster. James was able to go home a few days after he was born, and for a brief period, we thought maybe James would not need any major medical intervention. However, within a couple of months his medical team became concerned about an upper airway obstruction. As is common with so many children with TCS, James's airway is smaller than is typical. Our lives seemed to shift again as we navigated the medical world to figure out what this smaller airway would mean for James. One of the frustrating things about a rare disease is navigating a medical system that isn't familiar, or well experienced, with your syndrome. Medicine is referred to as a "practice," but having a rare disease makes it clear how much of medicine comes down to experience and opinion. There are no evidence-based treatment pathways for TCS, so having the opportunity to see an experienced and respected craniofacial team is invaluable. CCA's financial assistance helped us travel to receive a second opinion from **Seattle Children's Hospital**. Now we know we have the right resources and a team that

is on our side. James is now one year old, and his medical journey is far from over. We're still navigating the waters with his new team. Soon we will learn if it will be necessary to perform a tracheostomy on James. While the thought of that fills us with anxiety and fear, we trust our medical team. We know that if the procedure is needed, it will be the best decision because we have a team that is ready to support us through that transition. In the meantime, we can spend more of our time and mental energy focused on our little guy, who is very active, rambunctious, and curious. We hold on tight to the moments that fill our hearts with joy and refill our cup. **Thank you CCA for giving us these gifts!**



children's craniofacial association

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The views and opinions in this newsletter are not necessarily those of CCA.

**If you no longer wish to receive this newsletter, please send an email to AReeves@ccakids.com or mail the label to the CCA office and ask that it be removed from the mailing list.

thank you to our 2022 facebook fundraisers:

names are listed in alphabetical order by the fundraiser campaign owner

- | | |
|----------------------------|--------------------------|
| 1. Amy McLaughlin | 23. Maureen T Margolis |
| 2. Brian B. Powlas | 24. Rhea Beach |
| 3. Cheyanne Sharpe | 25. Samantha Leanne Mays |
| 4. Connie Williams | 26. Stephanie Moore |
| 5. Dan Blair | 27. Steven Tyler |
| 6. Dana Fernando | 28. Teaira Alexander |
| 7. Ellen Weiss | 29. Thelma M Cormier |
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| 12. Jennifer Evans Smith | |
| 13. Joel Brusk | |
| 14. Katie Hartke | |
| 15. Kellie Lloyd | |
| 16. Kelly Cunha | |
| 17. Kike Vicente Lopez | |
| 18. Kristen Golden Lambert | |
| 19. Kristine Deily Dale | |
| 20. Lisa Bowers-Alters | |
| 21. Lisa Stanford | |
| 22. Liz Froba Alexandrou | |

create your own facebook funder

Facebook is a great way to raise funds for CCA Kids. Facebook takes 0% in fees and you can set up your fundraiser with a few quick clicks.

- visit: www.facebook.com/fund/ccakids/
- click - Raise Money
- click - "Non Profit" and then search for "Children's Craniofacial Association"
- click: Children's Craniofacial Association
- select - a goal amount and end date
- click - Next
- enter - a title for your fundraiser - Birthday or CCA Fundraiser, etc
- enter - tell your audience why you are raising for CCA (We already have some words in there but it is all totally customizable)
- click - Next
- select - a cover photo - we have a bank of photos to choose from or you can upload your own
- click - Create

IT'S THAT EASY!

thank you