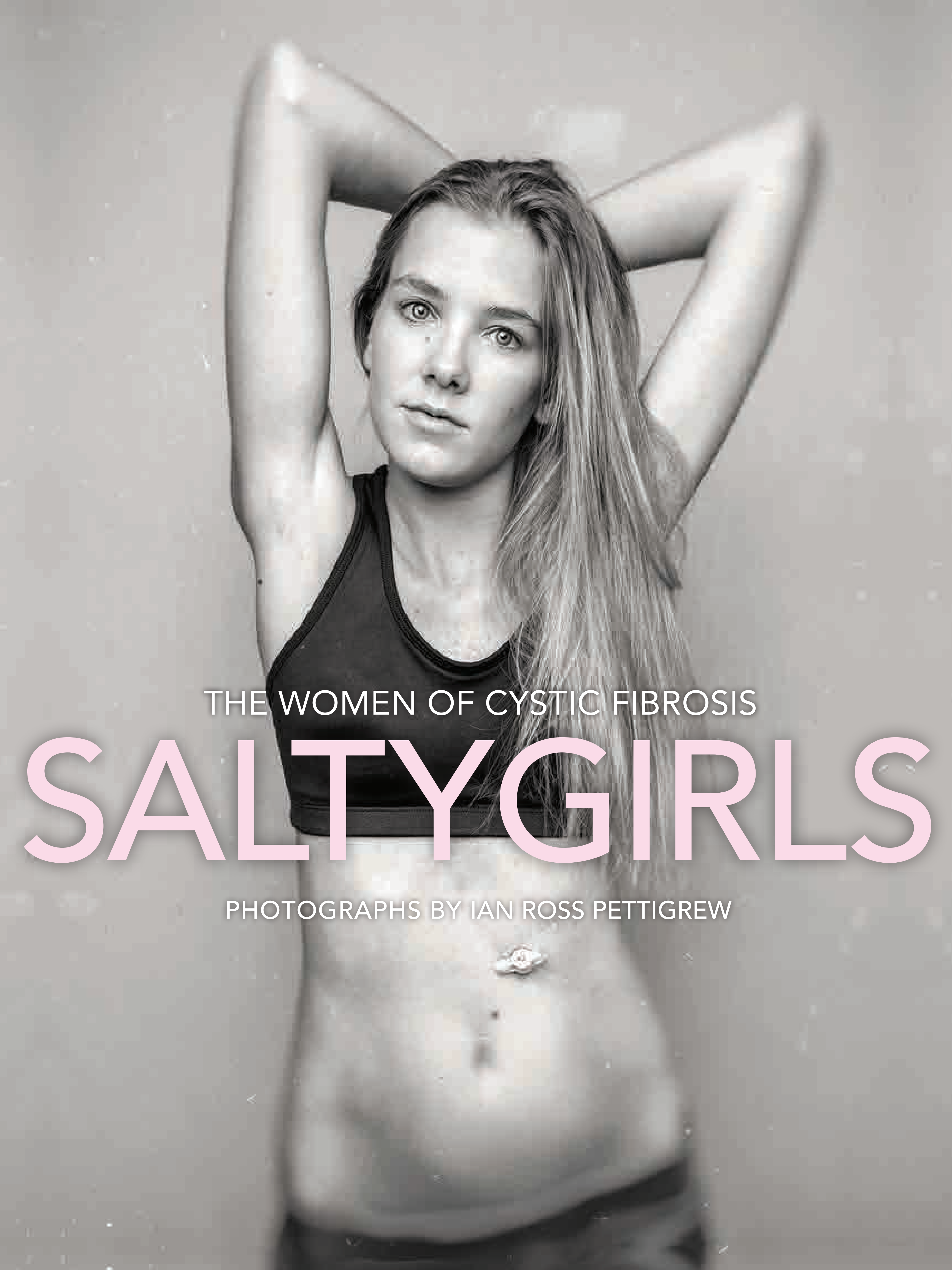

THE WOMEN OF CYSTIC FIBROSIS

SALTYGIRLS

PHOTOGRAPHS BY IAN ROSS PETTIGREW

SaltyGirls was made possible with
the generous assistance of

Cystic Fibrosis
Canada™

In memory of
Jennie Reeves Ashe, Erin Phillips, Katie Kelly,
Maria Umpierre, Cristy Lopez, Stephany Nichole Mallicote

SaltyGirls Forever.

Safety Precautions and SaltyGirls

Disclosure: Ian Pettigrew was diagnosed with CF at age 38, over 8 years ago. He has regular checkups at a CF clinic. He is neither on medication for his rare genetic CF combination, nor has he ever presented with lung disease or infections.

Cystic Fibrosis (CF) is an inherited disease that affects mainly the lungs and digestive system, resulting in a buildup of thick, sticky mucus that compromises the overall health of those with the disease. In the lungs, the buildup of mucus allows bacteria to grow, causing chest infections and irreversible lung damage. Through many years of research, the CF community is gaining better understanding of how these bacteria affect the CF population, and the complications that arise from them. The US Cystic Fibrosis Foundation's Infection Prevention and Control Guidelines for Cystic Fibrosis recommend that people with CF remain separated from each other to minimize the risk of cross-infection. In an effort to protect the entire CF community, Cystic Fibrosis Canada endorses these guidelines, while recognizing the rights of adults with CF to make their own informed choices.

To address the infection control guidelines, efforts were made by the photographer to minimize any risk of cross infection. None of the women self-identified as being infected with any high risk bacteria (such as Burkholderia cepacia complex). All photo shoots were staggered a minimum of two hours apart, and the women were never in contact with each other. Also, when requested, surgical masks were worn during the shoot and all surfaces were wiped cleaned between sessions. When specifically requested, a minimum distance was kept between the photographer and the women.

Topics that dominate the Salty Girls' conversations were loneliness and isolation. Many of these women made the conscious decision to meet in person, or as a group, outside of the recommended infection control guidelines. They believed that ending the personal isolation outweighed the potential risks of cross-infection. They were aware of the risks and it was their decision as informed and consenting adults.

SALTYGIRLS : The Women of Cystic Fibrosis

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Introduction

Imagine what it is like growing up as a woman in today's society, where the media demands perfection, and where body-shaming has become all too prevalent. It's a constant struggle to maintain this concept of 'beauty'. Now imagine you have double lung transplant scars, meconium ileus scar, liver and pancreas transplant scars or PICC line and mediport scars. Because CF affects the digestive system, the appearance of being underweight is prevalent, leading to snarky observations of "anorexic". This is the reality for many women with cystic fibrosis.

In this book the Salty Girls challenge this norm, and strive to put an end to body shaming. NO MORE feeling embarrassed or ashamed of their bodies, The Salty Girls have now inspired other women with CF, from literally all around the world. They embrace their body's scars and all, to inspire women everywhere to do the same. These women truly are the epitome of remarkable strength, enormous resilience, and unique beauty both inside and out. This book is not only about raising awareness for Cystic Fibrosis, but is a call to all women to stand together and be bold and know that they are beautiful.

Salty Girls is the logical evolution of the first book, *Just Breathe*, which focused on portraits of adults with Cystic Fibrosis. Around this same time I saw the photo of model Bethany Townsend, who suffers from Crohn's disease, and another model with the skin disease vitiligo being interviewed by Tyra Banks. I thought it's time for a model with CF. I know what these woman go through on a daily basis - everyday is a struggle living with Cystic Fibrosis. And, to the uninformed, it's a somewhat *invisible* fatal disease. With this book it's invisible no more. Every one of the women that participated wore whatever SHE wanted, posed the way SHE wanted - as an expression of themselves, how they wanted the world to see them.

The stories here are real and powerful. It's the Salty Girls, in their own words - **Bold, honest and beautiful.**

For those new to this project, **Cystic Fibrosis is a fatal, genetic disease with no known cure.** An inherited disease, CF affects the lives of almost 35,000 people in North America and nearly 70,000 people worldwide. Those with CF have a defective gene that causes the body to produce unusually thick and sticky mucus, which clogs the lungs causing chronic infection and blocks digestive enzymes from leaving the pancreas. People with CF have more chloride (salt) in their sweat - the CFTR chloride channel is defective, and does not allow chloride to be reabsorbed into sweat duct cells. Hence the title Salty Girls.

Some of the scars born in these pages are from double lung transplants, liver transplants, pancreas transplants, PICC line scars, feed tube scars. The list goes on. Each scar is a battle wound, and a testament to the will and fortitude of these fantastic women.

“ Sounds like you’ve got a cold.” “Are you sick again?”

“You should really see a doctor about that cough”
These are all comments I hear from people on a daily basis. Of course it’s understandable. I am a receptionist at a spa and talk to handfuls of clients every day, most of whom do not know me personally. “But you don’t look sick” is a common response I hear from people when I tell them I have Cystic Fibrosis. “I’m so sorry” is another response I hear and is also my least favorite. But my question to those people is... “Why are you sorry?” In my 26 years living with CF I have had my share of ups and down. I’ve been hospitalized countless times. I’ve been lucky enough to only need sinus surgery. I’ve never needed a port or feeding tube, although I came close to it as a child. I’ve been super vigilant with my medications and treatments for most of my life which has helped me maintain good lung function. Having CF takes a toll on the body not just physically but mentally as well. Most of my CF scars are more emotional than physical. Throughout my adult life I’ve struggled with anxiety and depression and often acted rebellious in order to cope. Being a Salty Girl has helped me feel comfortable in my skin (CF belly and all!) and realize that I am not alone in these struggles. Each and every one of us Salty Girls is unique.

We all have a different story, different CF mutations, and different body types, but together we create a CF family like no other! We are sharing our stories and bodies with the world proudly, in the hopes to raise more awareness for this crazy disease we all live with. So to those who say they are sorry...Don’t be! Having CF has helped define who I am in the best ways possible. I strive to be the best person I can be. I’m ready for anything that comes my way. I take no day for granted. I enjoy life. I am happy being involved in this project has changed my life and for that, I am forever thankful.”

Emily

“I have this odd fascination with scars and the stories that they tell. Growing up my mom told me to tell friends, jokingly of course, that I was bitten by a shark. She thought doing so would prevent me from being self-conscious of the lengthy surgical scar that spanned my side. It worked.

Inevitably though, with age, insecurities of living with a “CF body” have still managed to rear their ugly head. Like connect-the-dots, PICC line and insulin pump scars pepper my complexion, while French manicures disguise clubbed fingers and Spanx suck in my “CF gut”. Despite thorough efforts to camouflage them, tubes leak and machines beep, exposing my secret. I wish I could just be normal.

Salty Girls has shown me why I cannot be ashamed of my body.

Each scar, tube, and device hint closer to the courageous battle that each one of us is fighting. They are life’s beauty marks that we wear as a badge of honor. They are the constant reminder that we are brave, we are resilient, and we are Salty. And we have the stories to prove it.”

Kate

“Pen to paper, I sit here staring at the blank page because my mind is consumed with too much anxiety to even know where to begin. The battle scars that I have represent my ongoing fight with Cystic Fibrosis. To say the disease and I have a love-hate relationship would be an understatement. I HATE Cystic Fibrosis but I LOVE the strength and the positive outlook it has forced me to live by. Lesperance, funny thing, my last name is French for the word “hope”, and some days, I feel like that is all I have. Although, most days I am overwhelmed with gratitude by all of the support I have with every breath I take. Comments about my body type, clubbed fingernails, and scars used to make me insecure

but now I am proud to own these scars, because without them I may not be alive.

At 23 years old and 49% lung function, I have a hard enough time trying to breathe as is. The idea of an expiration date triggers my anxiety so powerfully it literally takes my breath away. Being a Salty Girl has been one of the best opportunities of my life. I have a beautiful CF family with a love so salty it would make any ocean jealous. Being a part of this project has strengthened my belief that no matter who you are, we should build each other up. Empowerment is a breathtaking thing. It has also given me the ability to be so brave that backing down isn’t even an option. The most life changing thing about being a Salty Girl is the courage it has given me to believe in myself, my health and happiness. Until CF stands for Cure Found, I will repeat to myself, Continue Fighting.”

Meagan

“ When people hear I’ve had a double-lung transplant they usually ask, “Does that mean you are cured from CF?”

The answer - no.

While my donor lungs do not have CF, I still do, it’s genetic. I continue to do nebulizers to keep my lungs clear, and take enzymes for digestion.

While I am enjoying my life since I have been able to breathe without the use of supplemental oxygen, and am grateful for my second chance at life, I still face many challenges. My body could reject the lungs at any time, and anti-rejection meds to prevent this present many side effects, and put me at high risk for skin cancer and lymphoma.

I’m adjusting to my new, more active life, and I am also getting used to a new body. Because of steroids, and the fact that I don’t burn as many calories anymore from keeping my lungs breathing, I have gained a significant amount of weight. I struggled all my life with being underweight so this has been a big adjustment. I’ve also earned many scars from my surgery and past procedures over 25 plus years since my diagnosis.

That’s why I wanted to be apart of the Salty Girls project. To not only give myself confidence, but also for other women with CF to see that you don’t have to be ashamed of whatever makes your body unique.”

Brigette

“ When I eat well and my weight is where it’s supposed to be, I have a visible belly...sometimes I’m asked if I’m pregnant or even more directly asked when the baby is due.

It hurts every time

- to a point where more often than not I wear loose shirts in an effort to hide it, and I can’t help but be self-conscious. I wish I had a body that absorbed these calories in a more “acceptable” way. In a society that works so hard to present the idea that women must look a certain very specific way to be worthwhile or loved, we will reject that and love ourselves anyway. In a society where too many men buy into the unrealistic ideals of beauty that media works so hard to perpetuate, we will stand and love ourselves anyway. And to the vocal few who will work so hard to slut-shame us for bearing a bit of skin, who would ask us to hide ourselves, our bodies and who insist that our souls need saving - to you I say FUCK YOU. The only thing we need to be saved from is the fate that Cystic Fibrosis presents to us. And if you can’t find it within yourself to set your sexual shame aside to support us, I suggest you step away and find a project you more closely agree with. Leave us alone - because we’re not listening anyway. You are absolutely powerless and you will be ignored. You are invisible. We are not and we refuse to be. I will not be ashamed of myself or my body. I will bare my skin and my soul in the hope that it will lift the spirit and mind of even ONE young woman with CF who questions her value and worth because her shape or her scars don’t match what she’s told she’s supposed to look like.

And it’s already working.”

Lisa

“ I was diagnosed at 3 with Cystic Fibrosis, my brother at 1. It’s comforting to have another person in my life that truly understands what CF can do to a person. My challenge with this disease has been more on the emotional side. I can deal with doing treatments and taking pills constantly, I don’t know any other way to live. But telling people that I have this chronic condition to deal with is much more stressful, I know that I can deal with it but I don’t know or trust that someone else will want to deal with it. I didn’t want pity or unnecessary worry to flood my way. It’s serious, but I’m dealing with it. I didn’t want it to define me. I thought even mentioning that I have CF was equivalent to complaining about it. I’ve since learned it’s not complaining and that it’s okay to let people know and not to hide it, because even though this could potentially take my life (notice the use of “potentially” I could also “potentially” get hit by a bus) it’s a part of me. Dealing with CF has helped shape who I am, like with any challenge you have in life, be it chronic disease or not. Physically I feel great and have insecurities like anyone else. At the end of the day I realize

I can’t depend on others to accept me, I have to accept myself.

Once you’re able to do that the right people will look at you and see you, not the illness.

Jessica

“Why does my body hate me?

I ask myself this question multiple times a day. I ask it when I wake up in the middle of the night coughing and gasping for air while my lungs and chest burn. Or when I’m in a hospital room attached to multiple IV antibiotics. I ask myself while I’m doing multiple breathing treatments in the morning and randomly throughout the day taking up time I could be using to play with my son or when I try to go on a walk and can only make it to the end of the driveway before I start coughing my head off. People point out the scar where my port is and ask about it which normally leads into a long discussion about my health. I’ve had people tell me they hate me because they wish they could be as skinny as I am, but they don’t know that I have a feeding tube and try to eat upwards of 4,000 calories a day to try and gain just one pound in an attempt to try and stay healthy. It’s hard to feel beautiful when you have to take 10-20 pills a day, have a feeding tube, scars, and being ferociously skinny despite your best efforts to gain weight. Living with cystic fibrosis is hard on your body and when you look in the mirror, sometimes you just wish for the conventional type of beauty you see in magazines. The Salty Girls project showed me that even though people stare and whisper (sometimes not so quietly), I am beautiful. That even though we may feel like our bodies hate us and are constantly raging a war against us, we are strong and we are beautiful the way we are.

Scars, tubes, and all.”

Lauren

“Do you see what I see?

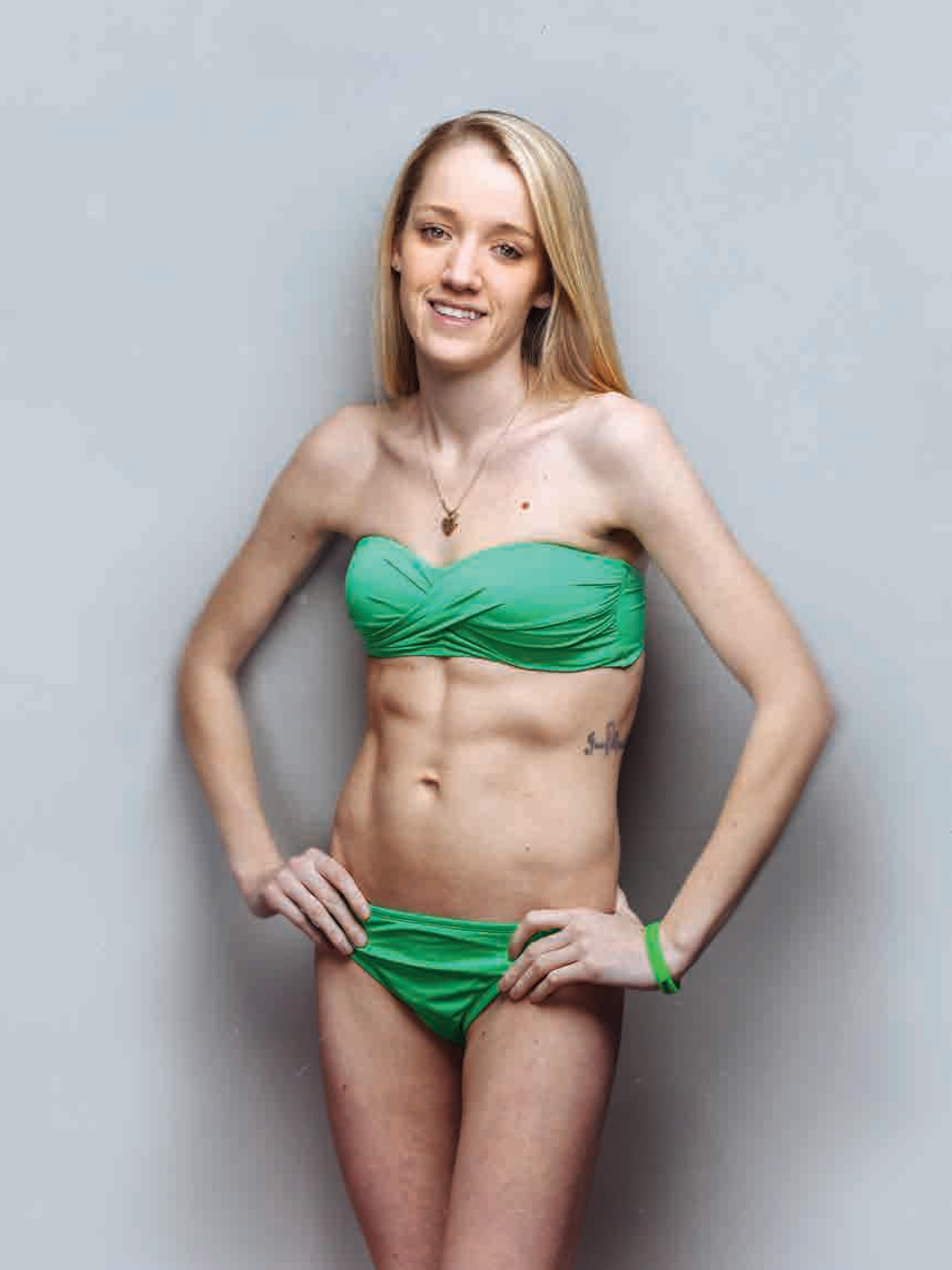
When you open the pages of the latest Cosmo magazine what do you see? I see people who according to society’s standards fit a mold. After they have been chosen they are made up, given clothes to wear that fit perfectly, or are fixed for the photo, then after the photos are taken they’re adjusted by photoshop to look perfect according to society’s standards. This is what our children are growing up aspiring to be. Fake. As a woman with CF I have never been able to live up to society’s standards because I have never fit the mold. I am too short, too skinny, my ribs are too big, I have a CF belly, I have clubbing on both my fingers and toes. That’s before the scars began. From multiple life saving surgeries come scars. Tracheostomy scars, dialysis scars, gall bladder and appendix removal scars, feeding tube scars, Port and Picc line scars. I have grown up with body image issues, I’ve never been comfortable in a bikini around my friends, lights off was never a question, sleepovers were not an option. Between treatments and bathroom issues, and all night coughing escapades. I used to choose the easy way out. The other side of this is with clothes on people assume we’re healthy. That is, until we cough, and we get the death stare, or we need to justify ourselves, or “You don’t look sick.” When I heard about Salty Girls I wanted in, it’s time we stand up to what society says is perfect and to prove every one of us are more beautiful then any fake Cosmo girl, or healthier than the ignorance or judgment we are subjected to daily. We are given one chance at this life and our scars are marks that tell us we made it through one more time. We are survivors, we are stronger than most, we inspire. I am proud to be a Salty Girl to show the world that inner beauty trumps all. CF does not have me, I have CF!”

August

“ Weighing in at a whopping 45 pounds by my double digit birthday,

it was that and the salty tears my mom happened to gag on while she was consoling my horrible yet regular stomach aches that lead to my diagnosis of CYSTIC FIBROSIS. Both of those topics are the reasons why I was excited to represent the many young gorgeous women who battle this bully of a disease. Many people step on the scale everyday wanting to see a smaller number than the previous morning. If it means eating salads all day long, its worth it! They look at those compilation of numbers to the left of the period and are thrilled when the numbers have decreased. Ever thought of the feeling stepping onto that scale every morning wanting nothing more then to see an increase? Eating more calories in a day then many do in a week to hopefully see an increase in numbers. Even if the increase were the numbers to the right of the period.... an increase is an increase no matter how small. Hearing comments about how women were created curvy are hard to hear when you have less curves then a square. Ordering the largest plate of food available and getting the death stare from every woman at the restaurant. Receiving comments about how jealous people are because of how skinny you look when deep down you just want to reply “want to trade?” In such a judgemental society its hard for any young girl or woman to feel pretty or sexy when they don’t fit the mold. The Salty Girls Project is helping to change that mold. Encouraging all girls, not just women battling a genetic disease, that the beauty about all of us women is the difference in each of us that makes us unique.”

Samantha



“Do you have any idea what it feels like to be betrayed every day by your own body?

To flinch every time an admirer puts their arm around you out of fear they will bump your g-tube? To be accused of being anorexic when you are desperately trying to gain weight? It is infuriating, it is terrifying, and it is a constant battle that you will never win. The point of this project was to show that we are comfortable in our own skin; skin scared from numerous tubes, countless IV's, and an array of surgeries. Looking in the mirror every day and being ashamed of what you see, embarrassed by the marks left by various attempts to make you better, or just plain angry that on the outside you look okay, while on the inside a war is raging, can take a toll on your soul. It is easy to become self-conscious.

Salty Girls aims to fix this by empowering women who have Cystic Fibrosis. It is a movement that was so desperately needed and it has been the catalyst for me learning to love my own body. When I first heard about the idea behind this project I was immediately in love, I knew without a doubt this was something I was meant to do. This was something I would leave behind for my son to see, so he would know how hard his mother fought and how beautiful he made her feel every day. I want future women with CF to receive the same hope and comfort that I got from this project. Had this been around when I was 15, wearing one piece bathing suits while everyone else was wearing bikinis, I would have had much more confidence.

I was one of the first women to do this shoot and paved the way for many more to come. I was not nervous - I was ecstatic. It felt natural, like this moment had always been a part of me. I hoped going forward, this project would inspire other women like it had me; to finally have a platform on which to speak, to stand up and be proud of their bodies and show just how beautiful this fight can be. I was not disappointed. What followed was an overwhelming response from the women and men of the CF community. A response full of positivity, admiration, and most of all, love. We share a bond so deeply rooted in who we are, how could it turn out to be anything short of amazing?

Becoming part of Salty Girls has been one of the most important experiences of my life. Having CF can be incredibly lonely. Not only are we isolated from the general population because of our illness, but we are quarantined from being with each other. Cross contamination concerns limit the relationships we form and the support groups that do exist offer little in comparison to human connection. Being next to another CFer in this book is as close as some of us will ever get to another CFer and for some of us, finding these people who know us inside and out, has ignited friendship on a level we simply never knew existed. Until Just Breathe and Salty Girls, I knew only one other CF patient. Through this journey, I have found my people: my cysters, my fibros, my salty companions, my heart, and my home. Words do not exist to describe what this project has done for my soul. And for that gift, that gift of normalcy, that gift of acceptance, that gift of love; well I simply cannot put into words how grateful I am.

Salty Girls has become exactly what I knew it would be. We have never felt more beautiful or inspired by our own bodies, EVER. The liberation this project has brought me is unparalleled by anything else in my life. There is rarely a day when I don't look in the mirror and see sickness. But when I look at my photo, surrounded by those of my amazing Salty Cysters, I for once in my life, am incredibly proud of the woman I have become – scars, tubes, and all. I am so proud of this group of women. We are strong, intelligent women dedicated to showing the world a thing or two about chronic illness. We deserve to feel sexy, we deserve to feel beautiful, and now we finally do.”

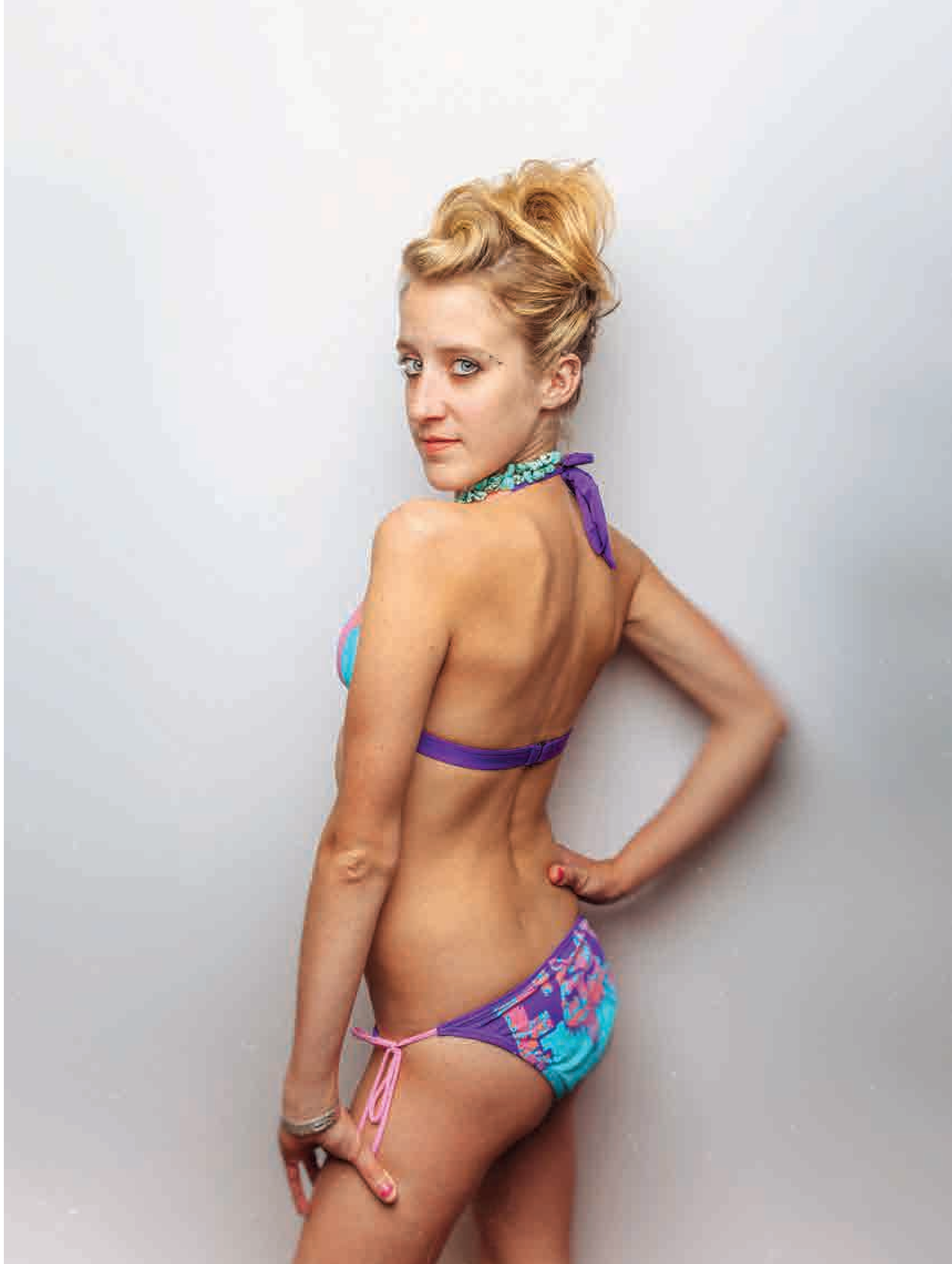
Gretchen

“Growing up, I always hid the fact that I had a lung disease. I didn’t want anyone to see or treat me differently. I would hide taking my medication and would rarely talk about being or feeling sick to my friends. As I’ve gotten older, I’m not hiding who I am anymore. Being a Salty Girl has allowed me to embrace my inner struggle with myself. Society sets a standard for how women are supposed to look. I’ve been told for so long that I’m too skinny and that I need to eat. Every day we hear these things that make us more and more self-conscious. I’ve realized that the biggest struggle that I have is with the person in the mirror.

This project makes me feel empowered as a woman,

and has given me the confidence to feel comfortable in my own skin. It’s so hard pretending to be stronger than you feel, and that’s one thing that is not only hard to live with but also hard to understand. It’s a mask that we all wear. Being a Salty Girl to me means, I get to take off my mask. This is me–I am 25 years young, living with Cystic Fibrosis, and although having this disease is mentally, physically, and emotionally scarring, it will not define how beautiful each of us are in our own skin!”

Megan



“This body I have is my normal. It is beautiful in its own way.

In a society where women are pressured to be thin by the media whether it be thru magazines, TV or with the constant bombardment of diet pills and fat loss supplements in advertisement, those with chronic illness are under a different type of pressure, one to gain and maintain. While this might seem like an easy task to some, someone with CF finds it much more difficult. I have been battling to gain weight and sustain it in order to have good health in the CF realm of things. My weight has now become such an issue that it might damage my chances of a lung transplant. My entire life I’ve heard comments such as “why are you so little?”, “you should eat more” and “must be nice to eat whatever you want and gain nothing”. These comments, while innocent, have killed my self-esteem. I find myself constantly measuring myself against others. Growing up like this was a huge challenge for me and I find myself always beating myself up over my weight and constantly wishing I could just be “normal” and have a “normal” body. While it may not fit society’s idea of a perfect body, it is mine and I will rock it with every breath I take. I encourage all women living with chronic illnesses, whether it be CF or another illness to take a good look at your scars and take notice in your individuality and how they make you beautiful. Being a Salty Girl isn’t something to be ashamed of, it is something to embrace and take pride in!”

Ashley

“ You look great! How do you feel?

That’s usually the beginning of every conversation I have with people who I haven’t seen in a while. I always respond with “I’m doing well”. Most of the time, it’s because I don’t want to start a whole 10 minute conversation about all my health issues. If I were to really tell them the actual story, I’d tell them how short of breath I am or how exhausted I feel. I’d tell them that I’m in pain because I just had a picc line placed earlier in the day for home IV antibiotics. Another reason why I don’t say anything is because I am strong. Yes, I complain and whine sometimes, but not enough to let it get me down. I have the scars on my body that remind me every day that this disease is awful. Yet I’m still alive. The scar going across my belly from a surgery I needed to get a blockage removed and the scar from a stomach tube I used to have makes me feel uncomfortable when I wear a bikini in the summer. The scars on both sides of my upper chest from ports for IV antibiotics, makes it difficult to buy dresses for special occasions. Huge scars that go down both of my arms from fistulas I needed when my kidneys were failing, which everyone can see when I’m at the gym lifting weights. Last but not least, the scars I see in the mirror every day from my kidney and double lung transplants. The Salty Girl project has let me feel beautiful, even with the scars I have. I see the other girls who have gone through similar things and I don’t feel so alone. They are all beautiful. I won’t be as uncomfortable wearing a bikini in the summer. I won’t hide my scars. I will embrace them. They are a part of me and show what I have been through living with CF. I’m alive and stronger than ever, and that’s all that matters.”

Justina

“But why me?

I’ve asked myself this a lot when I started to understand my disease more. Why did I have to have CF? Why me? Why do I have to be so skinny? Why can’t I be like her? Why do I have to be in so much pain all the time? I’ve asked all these questions to myself countless times and I’m sure all CF’ers go through this. I used to hate my body and myself because of CF. No one understands how tough this disease can be and how it can mess with your mind daily. I was never confident in myself. But since Salty Girls I no longer ask those questions. I for once feel proud, confident, and sexy even. I look at all us CF’ers and see people who fight daily but still look at life beautifully. Our CF affects each one of us differently, some have had transplants, gtubes, feeding tubes, picc lines, and scars. But Salty Girls helps us not to be ashamed of that and to see that those scars are tiger stripes! We should be confident and proud of how far we’ve come! People need to see these pictures and write ups to understand CF - we are fighters and we don’t give up! I’m so proud to be part of this project and all it stands for! I see my picture all the time being shared and everyone telling me I’m inspiring! It’s pure bliss.

I’m Shelia Rose. I have cystic fibrosis and I’m a Salty Girl. Get ready world because the saltiness is coming to you!”

Shelia

“ My name is Ashley Konyn. I’m a 27 year old CFer. This project was so much fun for me. It helped spread awareness that CF is now not only a children’s illness, we are living to become adults. I live in New York and have a very strong support system. My husband fights along side me and helps me to stay CF strong!! Ian came to New Jersey which was the closest state to me to meet and take pictures. My friend and I made it into a road trip I was really excited to model and help spread awareness. We had a lot fun during the photo shoot. This project really meant a lot to me and I love to model. Showing off my scars in a sports bra and bathing suit bottoms was great,

it really helped with my confidence.

The pictures came out so nice! I’m lucky to be a part of this project and to still be here fighting. This year has been difficult because I’ve been very sick. My pfts (pulmonary function tests) dropped from 50s to 30s. This was very scary for me. This is the lowest my numbers have ever been. I put my gloves on, kept fighting and got my pfts back up to 51. This is still low for me but I’m still fighting and believe and have faith I can get them up more. This project helped give me strength and I really enjoy being in these books!! Great Job Ian this project turned out great!!”

Ashley

“I have always been a quiet one. I will be cordial and polite upon meeting new people, but I will definitely be shouting a string of profanities in my mind while I smile and nod at you. Salty Girls changed that completely. With the women I had the priviledge of finally meeting through the project, I did not need to have those defenses up. I did not need to shout profanities in the confines of my mind, because I was free to shout them out loud, which all the women expected, which was fucking awesome! There was no way I could make myself invisible to these women, and I had no desire to. When Ian asked if I would participate in his second project my immediate thought was, “Why me?” Salty Girls is about these strong, beautiful women living with Cystic Fibrosis. I only have Cystic Fibrosis. I have never used “strong” or “beautiful” to describe myself. To be honest, I still do not. I cannot look in a mirror on a daily basis or semi regular basis and say, “Megan, you are beautiful.” I just cannot lie to myself. Being surrounded by women that staggered me with their undeniable beauty was very intimidating.

And it hit me.
These women truly
think I am as beautiful
as I feel they are.

They told me through social media and, finally, in person. And, for once in my life, I actually believed them. I believed them, not for the moment, but forever. It was a sobering moment. A moment of clarity. A moment I will remember for the rest of my existence. These women are all unique in their beauty. Scars, ports, buttons, cannulas, oxygen tanks, vogmasks. The sisterhood, pardon me, CYSTERhood that formed was instantaneous. These women understand exactly why I felt alone for 3 years. I understand their pain, and they understand mine. I can cry in front of them. My defenses have no hold over me when I am with them. We truly do empower and LOVE each other in a way that words cannot accurately depict. The love and bond I feel for each and every one of these incredible individuals is the strongest thing I have ever felt in my life. My heart swells with insurmountable love and affection when I take a moment to think about these ladies and what they have done for me. My cysters and my sisters. They have all changed my life and changed who I am as a person. It is simply irreversible. I love all of you. Always and forever.”

Megan

“ All my life I kept me having CF a secret.

I thought if people knew I had the disease they would look at me different. I always thought being different would make people for sorry for me. On December 19th, 2014 I came out in a silent Youtube video sharing with the world I have Cystic Fibrosis. The video went viral 13.3 million saw it. We have been featured in many articles and a few tv shows. Never in a million years could I see myself as being a spokeswoman for Cystic Fibrosis or starting my own foundation.

I feel so blessed to have all of these opportunites and the chance to be a Salty Girl and raise more awareness is an even bigger blessing. This project and raising awareness is all bigger than me but I’m so glad I’ve had this opportunity. **Making a difference is something I have always wanted to do.** Thank you to everyone who has made my journey, foundation, and opportunity bigger than I have ever imagined.”

Christina

“ I feel liberated and free!

Having Cystic Fibrosis can sometimes feel like your chained to your bed or the bathroom. Constantly in pain from what you ate or short of breath and can’t get up to go to work, or clean the house, or play with the dogs. Always feeling trapped with limits that doctors and society place on you. “You’re too sick to do that”, “well you dont look sick, YOU dont have CF.!” I’m so proud to be part of something that focuses in on womens beauty and strength. When I heard about the salty girls project I was so excited and honored to be a part of something so inspiring. I wanted the image of me to inspire and say “Ha F@#K you, CF. I’m here, I’m hot, and ya I’m sick but you ain’t getting in my way of my living!!”

After taking my portrait I felt so liberated and free! Like nothing, not even CF, was going to stop me from feeling beautiful!! I’m getting married in 2016 and planning my wedding has been such an emotional journey. I never thought I’d see my wedding day. I never thought I’d have a chance at a real life. And it feels great to say “...ha ha ha told ya so!!” Bring it on CF!”

Ashley

“I have often wondered why me? Why can’t I look like the girls in the magazines? Why do I have to have these scars?

Ever since Salty Girls, I have become confident in myself.

I’ve realized how our world has created a false and unrealistic image of what women should look like. I’m able to show that even with a life-threatening illness; I am strong, beautiful, and incredibly loved by Jesus. Because of my illness, I have been rejected and abused emotionally. My fellow Salty Girls and I are taking a stand against the image our world has created. We all have different scars and stories, but we are all similar. Each one of us is beautiful and strong.”

“There is nothing more rare than a woman unapologetically herself, comfortable in her perfect imperfection. To me, that is the true essence of beauty.” - Dr. Steve Maraboli

Emily

“ I remember when a kid asked me “Does cystic fibrosis hurt?” I laughed and said no instantly. When he walked away I actually thought about it.

Yes cystic fibrosis hurts. The pain is horrible.

From the physical pain of waking up after your fourth sinus surgery, feeling like your head will literally explode if you cough. To the daily sharp pains in your ribs that take your breath away. But it’s the mental pain that hurts the most. It’s getting those dirty looks when you’re coughing in a restaurant. Or when guys look at your bones sticking out of your back and say how disgusting it is. It’s that person that looks at your port and give you that sympathetic look as if you’re going to die tomorrow. You look at my body and see it failing me. Do you not think I see it? That I don’t feel it everyday? But Salty Girls changed that. My body isn’t failing me, it’s holding up through all the things that have threatened to break it down. Our scars that we didn’t get a choice to receive are just as beautiful as our tattoos that we pick out ourselves.”

Stephanie

“But you don’t look sick.

This is the sentence I hear more often than not, when someone finds out that I am progressively ill. In reality, my life makes me feel anything BUT beautiful 99% of the time. My beauty routine consists of finding tape that doesn’t burn my skin. Finding foundation shades that hide the subtle yellow from my liver, or provide fake glow when in need of new infusions for my blood. Injecting my glucose monitor in an area of bruised flesh that doesn’t compete with the feeding tube in my belly, or the portacath in my chest. Concealing my fingertips when they turn blue, or pretending that I don’t psychoanalyze the perils of walking in heels whilst carrying an oxygen tank (not advisable, if you’re wondering). Choosing earrings that don’t get tangled in my cannula, or battling the rash on my face from the bipap mask which often helps me breathe. There is no bell to ring when we conclude a round of treatments. There is no congratulatory dance when we dip into temporary remission. There is no pause... there is no respite... there is, essentially, no time to ever feel beautiful. The Salty Girl Project gives us the chance to pretend we are normal girls who don’t hide scars and fake smiles. Normal women who can love the very entity that causes our pain in the first place... our bodies.

We only have one body in this life, and even though ours is often the catalyst for a life-long internal war... it’s still ours. It’s still us. We are still a “me”, and for this brief moment of salt, sass and somatic beauty... We can make peace with our own skin.Why? Because whether it looks sick or not, that skin is infinitely beautiful... and so are we.”

Bailey

“People are always surprised when they find out that I have CF. They tell me that I am so positive, or that I look great, and I agree for the most part. For years, I have taken steps to voluntarily conceal my disease. Not because I am ashamed, more so because I wanted to live some of my days without the constant reminder of CF. My port has been strategically placed so that it is covered by clothing the majority of the time; I hold in my cough in public and I can sneak pills around strangers like no other. Few people have actually seen the times I am draped over the toilet, losing my lunch from coughing, or the times I crawl back into bed after my morning shower just to rest, achy and out of breath. When I step outside of the comfort of my own home, I am expected to be a healthy, vibrant and productive 24-year-old, but some days I feel anything but that. I feel sick. That is the downfall of an invisible disease–a physical body can be misleading.

It can be painful to live a double life,

to never feel like you are meeting expectations, to look one way and feel the opposite. Salty Girls is officially blowing my cover.

I wanted to be a Salty Girl because I think it takes an incredible amount of strength and faith to look down at the figure that can fail and disappoint you everyday, the form that is pumped full of drugs in order to work, and still believe it has been beautifully and wonderfully made. To love the thing that causes you pain is humbling. Women with CF do this daily. I do this daily. We are proud of our bodies because they work their skinny butts off to breathe, digest, absorb and fight. They are beautiful in a powerful way. They are resilient. They have scars. Above all else, that is why I wanted to be a part of the Salty Girls project. It is time to show off my strength. I want to peel away the secreted layers and show that women with CF are physically beautiful (that is obvious), but more importantly, we are beautiful where it truly matters: internally.”

Janeil

“I have always been skinny and for a while we thought I was just taking after my mother. Simply because she has always been naturally skinny. But we found that to be untrue when I was 5 years old. I was diagnosed with Cystic Fibrosis. That’s when my life, as I knew it, changed forever. I started vesting (bd’s), nebulizing, and pills lots and lots of pills.

I don’t have as many scars as some of the other CF girls but it’s still difficult to walk out in public with what scars I do have. People are so quick to judge whether you have one scar or five, I have learned.

Soon I will have more scars from my transplant

and I will proudly show them off every time the opportunity presents itself. There have been many times I’ve thought if only I weighed more, or was taller, or prettier; but I was built this way for a reason.

Being a part of the Salty Girls has been so amazing. I have met so many confident beautiful CF women. Just watching how much this project has helped so many other women has really been humbling. I didn’t think such a simple task (standing in front if the camera) would cause such a big reaction and be helpful to so many women. Even with being a Salty Girl myself, I am still not completely comfortable in my skin but I will get there. One day!! I will wear my scars with pride as they have shown me what I have overcome. This, I know, is what makes me so strong and proud to be a Salty Girl.”

Shelby

“I look at my healthy peers and all of the things they’ve accomplished and sometimes it’s a significant downer. Other people in their 30s have their own houses, they’re married, with children, and with full time careers. I’m still living with family (though that’s in the process of changing), unmarried (though I do have a wonderful boyfriend), I don’t have children, nor will I ever, and I am unemployed. I struggle with these things on a fairly regular basis.

That being said, when I look at it objectively, I know I have plenty of accomplishments. They just present much differently than those of healthy people. My accomplishments aren’t all obvious in my daily life, but they’re obvious on my body. I survived abdominal surgery at two days old, PICC lines and three separate port placements, two sinus surgeries, and a hysterectomy, among a few others. I survived a terrible allergic reaction to an IV antibiotic that almost killed me in 2012. I have survived CF for 31 years (and counting).

What looks like scarring and crazy surgically implanted medical devices to you is survival to me.

Sometimes it’s difficult to feel beautiful with CF, but when I consider all my body and mind have endured, I think “possessing qualities that give great pleasure or satisfaction to see; delighting the senses or mind” fits quite well. Being a Salty Girl has helped me see that.”

Emily

“ You’re too pretty to be coughing like that.”

My entire life thus far the phrase “Your’e too pretty” has been spouted off at me regarding various aspects of my illness. Apparently I’m too pretty to have to go through having needles stuck in various parts of my body, to be on I.V. antibiotics, to have chronic sinusitis, to cough, to be out of breathe, or to be in pain. When I hear this I want to scream. Having had CF all of my life I’ve had many days where I feel ugly. Some days I feel broken and battered. I have days where I feel as if life dealt me an unfair hand and find myself jealous of “normal”, healthy, people. I have to remind myself everyone is fighting some type of battle, whether its apparent or not.

My battle with Cystic FIbrosis is a ghost to most people, for they are unable to outwardly see the inner struggles that come along with this disease. I spent nearly 4 years of my life being mortified of my port-a-cath scar on the upper left side of my chest. Eventually I learned to accept, and ultimately, wear my scar with pride. I’m a survivor. Illness does not discriminate.

Being a part of the Salty Girl project forced me to be comfortable in my skin, scars and all. It made me feel beautiful. My perception of myself at times may be a bit flawed, but ultimately, I am empowered by this disease. It pushes me to keep on, to truly live in the moment, and in those fleeting moments- feel true acceptance of myself in that moment.”

Jesse

“ I feel the most vulnerable when I am naked.
I feel the most beautiful when I am naked.

Many times with CF you feel as if you are just a body. Our disease takes over our bodies in so many ways, when nothing is feeling quite right and you are weighed down by medications and treatments, one thing after another, it’s very difficult at times to feel proud or even thankful for the body that you have.

I struggled with body image since I was young. For such a long time I did not take care of myself or my body. I had to somewhat repattern my thinking and keep reminding myself that if I was going to live a healthy life, or even just survive at all, I needed to accept myself in my own skin and tell myself that I’m going to have to be alright in my own body if I’m going to do this. It’s still a struggle each day. With CF you cannot compare yourself to others, we are going to look different, gain weight in different ways, and feel differently but we also have the skills and strength to overcome hard times and learn to accept life (and our body) as it may be. Where the mind goes, the body will follow.”

Rowan

“As I look in the mirror, I see this distorted body I have been given and everything it has endured. The scars show the hardest moments of my life, and serve as a reminder of what CF does to its victims.

From multiple PICC lines, two port a cath, three transplants, ten chest tubes, a feeding tube and a tracheotomy you can understand why a Salty Girl would want to hide her body from the world to see. Nonetheless, I have never feared being exposed. I'm thankful that my body image is not something I really struggle with but I know the world makes it very hard for everyone to feel secure in their own skin.

When being asked to be part of this project, I felt honored. I was criticized by my family for exposing myself to the world in this way but I felt like it was something I needed to do.

I wanted to inspire and empower other CFers to believe that their bodies are nothing to be ashamed of.

It should portray your life story, the obstacles you have overcome, and you need to be proud of that.”

Cristy

“I am a 21 year old wandering spirit in this crowded world. I have seen much happiness and sorrow with my illness, but the sorrow has become more prevalent in the recent year.

My name is Maria, and I have Cystic Fibrosis, diabetes, gastroparesis, osteoporosis, and chronic sinusitis. Cystic Fibrosis is the tip of the iceberg that tracks down a list of medical problems I currently have, and can potentially have in the future.

I am currently waiting for my second double lung transplant. These seven years were a long one, and perhaps this journey will present a newer me.

This newer me began with Salty Girls; because I have grown up being insecure of my scars. I was presented an opportunity I had secretly desired by Ian Pettigrew, (a friend who has Cystic Fibrosis as well and is allowing many adults to present themselves forward for awareness), to be allowed to show my scars and take photographs of them. I wanted to show the world, and to myself, that there is nothing to be ashamed of when you have body image issues, ranging from size to scars to freckles, and anything you can possibly think of.

Salty Girls showed me that I was not alone in having scars that I have been afraid of showing, and that provided me the comfort I needed from not only my fellow CFers but also to myself. From when I made that stance to treat my body kindly, (as it needs it more than ever) it presses on today.

I hope that from reading the words of women who have had little accidents, surgeries, and whatnot gives you the confidence it gave me. I hope that it gives you, no matter what gender you are/identify yourself as, or what size and color you are, you feel beautiful.

There are more of us (you and I) struggling in this world to achieve society’s “perfect” body,

but let us be real, we only have our bodies to love - and that is the perfection that is enough to love ourselves.”

Maria

“I have wasted a lot of energy trying to hide every shred of Cystic Fibrosis from people. It started when I came home from the hospital at 12 years old with a tube hanging out of my stomach. It compounded when bathing suit season started and I now had a feeding tube and a central line scar to camouflage. I've worn countless one-piece bathing suits with ruching across the middle to hide my feeding tube. I modified numerous swimsuit tops with added tank tops underneath to hide scars.

As I've gotten older, I have become much more open about having CF. I made some amazing friends, who helped me really learn to love my scars. I used to worry about people asking me about my them. My friends helped me come up with crazy answers like, “I got in a knife fight in my foster home.” I eventually stopped caring about them and stopped worrying. I've found people rarely ask, if they do, I just tell the truth.

I have since started taking pride in my body and started playing roller derby.

Derby has pushed me to see what else I can make my body do. I go to crossfit knowing I will probably always be the last one to finish a workout. I will cough, sputter, and hyperventilate through every workout. People always ask if I'm ok; I just nod and keep moving. Someone recently asked about my cough, after finding out I have CF she was surprised I was doing crossfit and not pulmonary rehab. I was lying on the floor in a sweaty puddle and between gasps I said, “fuck pulmonary rehab.” She grinned and gave me high-five.

I will always be in a battle with my body. I am always pushing it to do something, whether it's just trying to get through the day of work, trying not to cough until I puke, or willing the hemoptysis to stop. I am thankful the effects of CF are not that obvious. I work hard to see myself as strong. I try not to stress over my belly that is sometimes so distended I look pregnant. I accept my slightly clubbed fingers and move on. I have embraced my scars. Everyday, I try to make my body do what I want it to do.

Being a Salty Girl reminds me I'm not alone. There are other strong women who deal with these same body image issues. I hope girls are able to look at this and see they don't need to hide.”

Jessica

“As fate would have it, my parents, two unknowing carriers of Cystic Fibrosis, fell in love and my family was created. We weren’t the luckiest family in the world, considering 3 out of the 4 children had CF, when statistically speaking, the chances are 1 in 4. Therefore, we were no strangers to long clinic days, countless medications, pokes, prods, bronchial drainage treatments, nebulizers, and test after test. From an early age, my dad told us that we would never carry a White Flag of Surrender, when it came to battling life with Cystic Fibrosis.

Having known no other life, diagnosed at birth, I was used to CF, and all the baggage it came with, that is, until 4th Grade. That year, we moved to a different community and my parents told my teacher about Cystic Fibrosis. One day my fellow students were educated on CF and learned the intimate details of my routine, diet, treatments, medications, etc. And on that infamous day, during recess, I went to join a group of girls to play. However, to my amazement, one of the girls yelled at me,

“Go away! You cannot play with us, disease girl!”

Telling my new class about CF back-fired, and I was left feeling mortified. From that moment, CF became a curse, a plague, a humiliating scar, rather than just one of those things I lived with. Over 25 years ago, on that day, CF became my Scarlet Letter. I tried to keep it a secret, believing that if it wasn’t known, I would be safe from the world and its cruelty. I no longer told people outside our family, not even my closest friends. I didn’t want to be labeled, and I certainly didn’t want to be the ‘disease girl.’

In 2010, my oldest sister Katie, my rock, my beautiful friend, and my CF warrior was exposed to health care acquired pneumonia. This lead to CF complications and eventually cardiac arrest at the age of thirty two. She was a fighter like no other, battled day in and day out with a radiating smile and a contagious laugh. Last year, I came close to death. My journey almost ended after my very first CF exacerbation, being exposed to Francisella Tularensis, dropping 30 pounds, given toxic doses of IV antibiotics, and losing half of my lung capacity in a series of random and unlucky events. But thankfully, with the grace of God and unwavering support, love, positivity and prayers from my beautiful family, friends, and medical team, I’m still here. Katie is smiling down at me, proud as ever that I overcame a horrible year, and won yet another battle.

I did this Salty Girl project for Katie and for my little sister Laura. She fights alongside me every day with her own CF journey. I also did this project for my husband Joey who is my constant encourager, never letting me give up, and for our beautiful 4-year-old daughter, Sophie. She holds my neb cups and pushes the start button on my machines every day. I also did this project for my twin sister, Amie who knows I want gummy bears while being hospitalized before I even know it myself. And lastly, I did this project for my family and friends who make me laugh in my darkest hours and still love me even when I have to cancel plans.

It’s only recently that I realized it’s ok to have Cystic Fibrosis, it is ok to be vulnerable, and rely on your friends and tell them you are weak. It’s ok to pray and trust in God to get you through the next hurdle. My stories, battles, tears, and scars reveal my strength, courage, and resilience. There is no shame in that! To all the children out there being excluded on the playground--there is no shame in being salty!”

April

“At the age of 2 I was diagnosed with CF. My parents knew our lives would be changed that day. My parents have always taught me to be thankful for what I have, there's always someone out there who has it worse. I had my first feeding tube put in at age 4. I'm 23 now and I lost count of how many feeding tubes I've had. I have had over 30 surgeries in my life. I can't tell you how many times I have been in hospital. After awhile you lose track. The nurses and staff have become family. I consume 20-30 pills a day just to keep my weight up and avoid infection. I come from a strong loving family. I have 2 sisters who I am happy to say are healthy. They are my reason why I fight. My body is my story. Some days I hate my scars. I feel like that is all people are looking at when they see me. But they are part of my story. It's a reminder of what I have overcome in life. Seeing my other salty cysters is emotional yet so beautiful. I am honoured to be part of this project and to have courage in my own body. Being a woman is hard as fuck but being a woman with CF is a struggle that I know I don't face alone. Every woman and girl with CF is a reminder that beauty can come in any way even with a few cuts or scars. I'm excited to feel pretty in my own skin. Bad lungs, stomach and all. While I breathe I hope. I have hope that more women and girls will wake up and know they are stronger because of their Cystic Fibrosis and they are beautiful!! I have the words JUST BREATHE tattooed on my body. It's a reminder that no matter what CF throws my way I can handle it.

I may fall down a few times but I will always get up.

Not just for me but for my family , friends and fellow cysters and fibros.
This book is going to change the face of CF. I'm proud to become
a part of CF history.
Just Breathe!”

Kelsey

"When I was younger I was always very self-conscious of the scar across my stomach that I received at birth, it was the only scar that I had at that time. All through Junior High and High School when my friends would invite me to the pool or the beach, I would say no depending on who all was going. See, not all my friends knew that I have CF and being in a bathing suit was not my favorite outfit. Explaining my scar and what CF is to every single person that asked me was awful; mainly because I hated that scar. It was like reminding myself over and over that I have a chronic illness. As I got older, you would think that feeling would go away. Well It didn't.

When I got pregnant with my son there was some complications that affected my CF in a negative way. To keep the story short, I ended up with more scars! Chest tube scars, feeding tube scar, a tracheotomy scar, and a lot of other little scars that I have no clue what they are from! I hated my body and these ugly scars more then anything! Then one day my husband told me that I was going to be doing a Salty Girls photo shoot. I had no idea what this was, so obviously I looked into it. At first I was not ready to be in a bathing suit taking pictures, but as time went on and

I saw other girls just like me with their scars that were able to be open with having CF, it made me feel so accepted.

I quickly realized that I wanted to be a Salty Girl! **I wanted to have a positive effect on some little girl out there and show them that there is no shame in having scars, that scars are a part of what makes us, a part of our life and what we have been through.** They show our strong personality on the outside, just as well as on the inside. I now look at my scars not as being reminded of my illness, but as a chapter in my life that I have fought and overcome.

Everyone's body is like a book, we all have our own story, and the scars on our body show the different chapters in our life."

Sabrina

“ Do you have a “type”? I once heard someone say that they’re attracted to “healthy ” people. I put healthy in scare quotes because I’ve grown to understand that “healthy” doesn’t mean healthy. Any fitness magazine will show you that a “healthy” woman is just a woman with curves “in all the right places” and a flat stomach. We live in a culture where women are shamed for their bodies, where girls want to start dieting at the age of 9 because they don’t like how they look, and where the average woman can name at least one thing on her body she hates, and that… Doesn’t sit well with me. For women with cystic fibrosis, not only are we forced to fit into a narrow ideal of beauty, but also we’re struggling to fit into a definition of “healthy” that is impossible to navigate because it’s utter crap. I mean, do I look healthy? Would you guess that I have the lung function of an 82-year-old smoker? That I do up to 4 hours of medical treatments a day and have to sleep propped up with pillows so I don’t choke in my sleep?

To be constantly told that you don’t look sick (as a compliment) when you know you’re quite the opposite of healthy is uncomfortable and even isolating.

You feel weird and “wrong”, and the tubes and scars on your body from being sick can hurt that much more when you’re struggling to look “healthy” on top of being healthy. So why am I putting myself out there? Honestly, I just want young women with cystic fibrosis to stop hiding their enzymes, start wearing that face mask on a crowded bus if you’re worried about getting the sniffles from the guy behind you, access your port or PICC on campus and attend lecture with your CADD pump and IVs. Flip through the pages of this book and feel represented, know that there is a community of us our here doing the same. Ultimately, don’t feel ashamed of participating in life in a way that works for you. I don’t have the privilege of having a healthy body, but I deserve to love what I’ve got, and so do you.”

Camellia

“I have alway been a huge believer that laughter is the best medicine. Laughing heals the soul and mind, which is probably why I haven’t gone crazy. Growing up sick is not easy in any sense. Like everyone, we have school with the normal middle/high school drama, then once we are of age, work. But, on top of all of that, we have to do hours of treatments and swallow countless amounts of pills to try and stay healthy. Staying healthy is literally a full time job. It is exhausting and by the time we finish doing all of it, we sometimes don’t want to go out with friends and just want to relax. That is something our friends and family can’t understand, until they are in our shoes. We get labeled “anti social” and boring. Doing all of our treatments and swallowing all of those pills still does not guarantee that we won’t get sick. We will, when we do, it requires hospital admissions, IV antibiotics and sometimes a bronchoscopy (where they stick a scope into our lungs to look at them on the inside). A lot of people think when we end up in the hospital it means that we are not doing what we are suppose to do. That is very untrue. I think that our friends and family not understanding that is one of the biggest reasons we all feel alone. What’s more, it is also why we feel so self conscious about the way we look. Because, we have scars and doohickeys that get constant stares and dirty looks. They have smooth, beautiful, unmarked skin. When they get sick, they just get to stay home and recover, and not in a lonely hospital.

When Salty Girls was in its starting days, I knew right away, it was going to be something I was going to be apart of. There was finally a group just for us women, who face different challenges than men. Being so self conscious about my scars, port and g-tube showing, seeing all of these other women baring the same imperfections I have, is comforting beyond measure. It has made me feel more comfortable in my own skin. It helped me see that yes,

these scars, tubes and ports are imperfections, but they are mine and they tell a story of strength, perseverence, resilience and triumpth.

Everyone in the world has imperfections. Some people, us awesome Salty Girls, just get to wear ours and wear them proud. Seeing these girls and reading their stories, has made a lot of that loneliness diminish. Some days, like every single girl, I still have moments of insecurity. Hell, even men have them, but I go out and I hold my head high and take life as it comes. Life is more than worrying about looks. In fact, people make looks important, when we all know life is about experiences and enjoyment.

I am beyond grateful for the continual growth of Salty Girls and us having each other to lean on. We are a family, we are cysters; We support each other and build each other up when one of us is down. Because life with CF is brutal, but they help make it worthwhile.”

Stephany

“I wanted to be a Salty Girl because I feel that it is a great way to show people that each and every patient with Cystic Fibrosis is different. No two Salty Girls are alike. Being a Salty Girl is a way of embracing and showing off that I have Cystic Fibrosis and I should not be afraid to rock it. Living with Cystic Fibrosis is a constant reminder for me to live each day to fullest and to not sweat the small stuff. We all handle Cystic Fibrosis in our own way; one of the ways I chose to cope with it was by getting two tattoos. One is a purple rose with the number 65 on the outside as a dedication to “65 roses” (Cystic Fibrosis) and the other is a reminder to just breathe no matter where this life takes me. Breathing can often be the most painful thing I did for that particular day, and other times taking a deep breath is the only way I can relax. People should know that Cystic Fibrosis is the reason I smile. Sometimes I use a smile to hide behind the pain that accompanies Cystic Fibrosis, while other times it is due to my positive outlook on life.

Most importantly, however, I smile because I woke up that morning breathing.”

Michele

"Live by faith....not by fear."

"When asked to join Salty Girls, I was ecstatic!! Reasons why? For one, who wouldn't want to be part of a group, composed of some of the strongest and most beautiful women that anyone would be lucky to know! For years, my confidence levels fluctuated drastically, but the minute I saw this project take off, my motivation to be a part of something to help it kicked in. I've been lucky enough to have a fairly healthy streak most of my life, and not really noticing my "monster" taking hold until more recent years. Fighting CF, everyday for a lifetime, can simply seem like torture at times. It makes many of us ask ourselves, "when will I ever catch a break?" Knowing the answer to that, leaves us the option to stand up, fight, spread awareness and show everyone that we are going to embrace our scars and pain, because in the end it simply means we were dealt this hand in life because we are strong enough to handle it! Second reason? I couldn't wait to meet so many members of the CF community, and gain a second (and pretty awesome) family. This is my opportunity to help and support so many whom are suffering, which I do in my line of work, but this allows me to help at a much deeper and more personal level. More reasons? Sure, lots.....too many to mention actually.

We can't be afraid of what people might say or think,

we can't change the fact that we have CF, or the outcome... but we can change the attitude we have towards it.

The Salty Girls project is going to do some pretty great things and I couldn't be more proud to be a part of it!!!"

Marcy

“Even though I was born with Cystic Fibrosis, I didn’t need frequent hospital admissions when I was younger. But as I got older (late teens into early 20’s), hospital admissions became more frequent. Eventually my veins became scarred in both arms due to having so many PICC lines placed. That’s when my doctor and I decided that it was time for me to get a mediport. I was skeptical at first - my first thought was “what would people think when they see it”.

I had the mediport placed in April of 2012 and it was one of the best decisions I ever made. It’s so much better than having a PICC line placed and to be honest, the particular mediport I got it isn’t very noticeable! It’s kinda funny because I’m usually the one who points it out - haha.

So if you have any scars - whether they’re big or small - don’t feel embarrassed or ashamed by them. You gotta wear them proudly.”

Gloria

“ My successful daily beauty regimen is dictated by my ability to do my vest, nebulizers, (intravenous antibiotics if necessary), while simultaneously straightening my hair and applying makeup. If I don't end up burning my ear, stabbing myself in the eyeball with eyeliner, or looking like a toddler just scribbled on my face- it's a successful start to my day! Women take long enough as it is, adding treatments on top only adds more of a time crunch for us CFers, so we have to make it work. So fellas, if you have a CFer as a girlfriend- be prepared to wait a few extra minutes, or hours.

Once I have the hair and makeup done, picking an outfit is just as time consuming. I went to fashion school in New York , and nothing else can be such a constant reminder to self image as much as a women surrounding you wearing the latest trends that I wish my body could be accustom to. When trying to be trendy, the way a shirt disguises my bloated CF belly, or the way a color could easily disguise a stomach bleed always wins my vote (Noted never to wear white. Thanks feeding tube hole). I was and will always be aware of my body's abnormalities. But, the difference is being as self conscious [to the extreme that I was] and the way I feel after the Salty Girl project. I am aware, but I have become more accepting.

The Salty Girl Project was an awakening that I needed. There's something about knowing [physically seeing] other women that go through similar struggles that's really comforting. You look at these women, and you see their scars, and that's only a brief mark of what they have been through physically and mentally from this disease. It was really tough for me to pose for a camera, because I have never felt my body was beautiful. I grew up believing what society tells us, or what I observed at fashion school- and I know that I will never the hourglass shape most women strive for. I don't have the ideal perfect body. And as time goes on, only more scars will be added.

When I saw these women posing for the Salty Girl project, I was drawn to them, they are all so beautiful. That inspired me in a way I can't even put into words. I didnt judge them based upon their looks, I see women who are embracing their lives, and struggles, showing their confidence and making it absolutely breath-takingly beautiful. I knew that if I looked at it this way, others must as well. I wanted to be one of these women; a woman with courage, confidence, and happiness beaming from her smile. I did this for younger women who go through the same physical tribulations and emotional turbulence I have been through. I did this for anyone else who has been called anorexic, when you know you have stuffed your face with 3-4,000 calories a day just to (possibly) gain a pound.

This project is about empowerment, strength, and feeling beautiful in your skin.

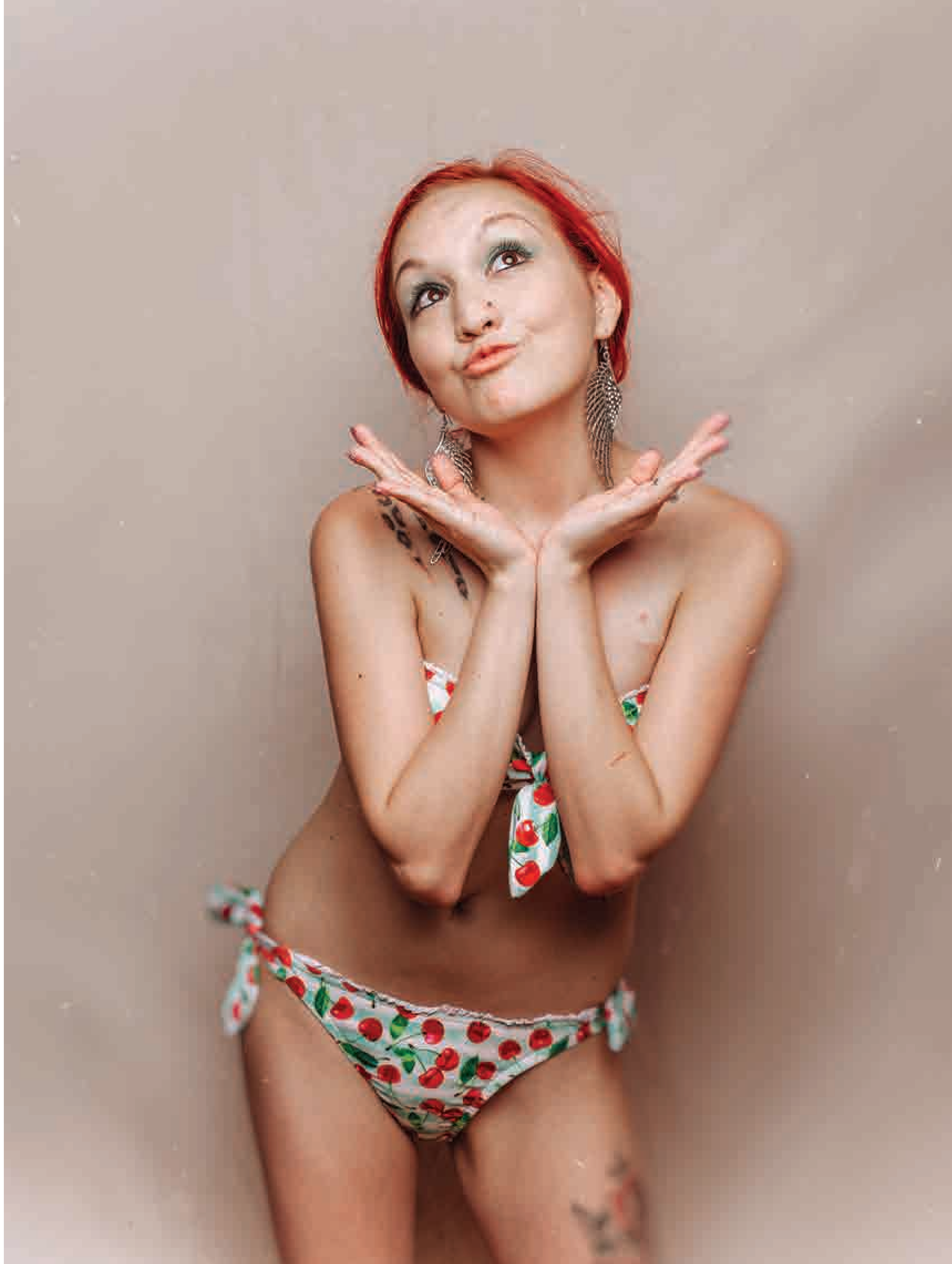
These marks don't define us, but tell a story. We may have scars, bruises, or medical devices on the outside, but the fact we walk away with them smiling shows a strength I didn't recognize I had until I became a part of this project. That's beauty in it's purest form. I am proud to be me, to share my story, and proud to be a Salty Girl.”

Rosie

“ Being a part of the Salty Girls project has impacted my life in such a positive manner that I truly feel like a super model.

I used to hide every scar, my port, and try to look as normal in public as possible. However, when my body started to get worse, I didn’t have many options with going out in public. I thought to myself, why should I hide anyways? People can stare and point all they want; it doesn’t bother me anymore. I remember when I had to take a type of medicine that made me very puffy and the rumors at school were horrible. They would spread rumors that I was pregnant and then when I dropped all the water weight, they would spread rumors that I had a miscarriage. What kind of society would think that is okay to do to someone? I’m fighting for my life and all people can do is spread hate. I actually feel bad for them because it means they are less educated and have no manners. When this project first hit the public, I wanted to be a part of the project so badly! The reason being is because we need this positivity in the world. We need to show women that have Cystic Fibrosis that you are BEAUTIFUL. Those scars and wounds show that you are indestructible. Doing a Salty Girls photo shoot gave me so much confidence and made me feel accepted. I used to model and it was brutal. I was either too fat or my scars were ugly. I was always rejected, but when I did this shoot…I was beautiful and I was myself! In fact, the more scars or bigger the tummy, the better! They say everyone wants to be a “Victoria Secret Angel”, I just wanted to be a “Salty Girl”! I am so excited to show women how beautiful they are no matter what they think is wrong with their body. The body shaming in this world needs to disappear because I prefer to see REAL women posing and showing how sexy they are versus photo shopped or unrealistic models. The best advice I can give in the dating world, find someone who is going to accept all of you on day one. I never thought I would get married because of CF. Now, I am married to my prince charming who kisses all of my scars and thinks I’m beautiful every second of everyday!”

Bianca



“When I first meet people the first thing they say is wow your so skinny. I wish I could eat like that and still have your figure. Or tell me I need to eat more bc I’m too skinny. Well the harsh truth is you don’t even know how wrong you really are. By all means you can have it along with all the lung, stomach, and sinus issues. The countless doctors appointments, daily breathing machines and pills. The days that you wake up just wishing to have a good day with no headaches and to have no pain. To just be normal. So when I am asked what it means to be a salty girl. It means if I could shed a little light on what cystic fibrosis is and how we might look healthy and fine on the outside this is a cruel disease that takes no mercy on the young. This disease does not discriminate, nor does it care about your life goals, age, looks or the hurt our family and friends go through. The chance to get to wake up in the morning and live another day is a blessing in its self. Being a salty girl means a lot to me.

So if I can be a role model to other younger girls with cystic fibrosis, to not hide or be afraid of this disease...

...to be comfortable in their own skin. If I put myself out there maybe the next person that runs into her will have more knowledge of what CF really is. This is our life and it’s a long hard road but I will tell you we are the most passionate, caring and big hearted people you will ever meet. We fight till there isn’t anything left. All we ever want to do is just live. So here I am putting myself out there. This is me and I’m proud of who I am and will keep fighting till my last breath. I am also doing this in honor of my sister Heather who passed away at 22 from CF. I fight for her everyday.”

Carmen

“At just over 120 hours old, my tiny 6-pound body was cut in half. Doctors removed my appendix as well as over 1/3 of my intestine in a surgery more commonly known for Meconium Ileus. This was just the beginning of my life and how fighting for it, was more important then how I looked. My parents then bought me a ‘Madeline’ book and doll about a brave young girl in Paris who had appendix surgery in the hospital. We shared a similar scar on our stomach. Madeline was small and outgoing. The story made me feel like I fit in since there was someone else like me, whose scar didn’t define them but empowered them. The more birthdays I celebrated, I began to notice I was different than others as more and more scars began to appear. Not only were there physical scars but emotional ones. After a date one night, the guy said “You could be really pretty if you lost 10-pounds”. Little did he know that those ‘extra 10-pounds’ were saving my life. The steroids I was on to help fight my infection caused me to eat more, as well as retain water which had given me a fuller and fatter face. The confidence I mustered up for that date was shredded apart in seconds. I had heard mean comments shot at me about my CF and about my appearances before but this one hit me particularly hard. Salty Girls is now my defense and the empowerment I once had but needed back. In fact with all of us girls we share more than just our disease. We are beautiful, smart and sexy in our own ways. Every scar we bare shows our life journey, and although some scars may have been more painful then others, they show our determination to go out in the world and fight everyday. Being a part of Salty Girls is my way of being like a “Madeline” doll to other young women, not only do we share some of the same scars, we don’t let them define us, we let our scars empower us. I am also hoping that Salty Girls Photo Campaign can bring attention to the Cystic Fibrosis disease. This ugly disease is masked by such pretty faces. Scars make humans unique, but scars keep Cystics alive. We don’t have these surgeries, procedures, blood draws, port-a-caths, picc lines, feeding tubes, insulin pumps, and chest tubes, because we want them, we have them because we need them. They are vital in fighting for our life.

I am proud to embrace every mark or imperfection that others may choose to stare at.

They show me that I have made it this far and I can and will continue to fight. I am beautiful, smart and sexy in my own way.”

Katie

“The hardest part about having Cystic Fibrosis is the ignorance. I could tell you stories for days of all the times that I was pointed out, publicly embarrassed, or ridiculed for having a cough, or having a distended belly, or having to administer IV meds through a PICC line in public. Friends and strangers taught me at a young age to keep quiet about my Cystic Fibrosis - I'd just nod and begrudgingly murmur that I have asthma or allergies or a cold that I couldn't shake.

Someone once said to me as I was walking down the hall of a hospital in heels, a dress, and the required face mask: “That mask doesn't go with that outfit.” I just chuckled uncomfortably and let him walk away. Even today I think about it and wish I had the quick wit to turn to him and say: “Well, my terminal illness doesn't go well with my life.” I always think: Next time it will be different, next time someone says something I will stand up for myself! But I never can. I am just so genuinely surprised by the things people think are appropriate to say to another person that it catches me off guard and renders me speechless and defenseless every single time.

Growing up with a terminal illness is lonely and terrifying - it's even harder when we are constantly ridiculed and embarrassed by the one thing that we can not change and will never be rid of. Being a part of the Salty Girls has reminded me that I am not alone, that there are so many adults living and thriving with Cystic Fibrosis, and that it's so much easier to fight a disease when you know so many others are doing it too. When I announced that I was a part of this project, the support from my friends was overwhelming - they were curious, inquisitive, and supportive. I have never in my life felt so comfortable and normal discussing CF with others now that I am part of such an empowering project. I am comfortable and confident sharing my story with others. I understand now the person that I am because of my Cystic Fibrosis. I am happy, I am a role model, and I have CF.

Salty Girls has made me extremely proud. I am proud of myself, I am proud of my courageous cysters, and I am proud that we are bringing awareness to adults with CF.

We're not cute poster children for a terminal childhood illness anymore - we are beautiful poster women that are surpassing all expectations.”

Jennifer

“Although my girls scout days are long time over, I can’t help but think of each one of my scars as a badge earned for strength, courage, and faith. As a teenager, I felt self-conscious about having a port in my chest and the scars it caused. Even though the scars have not faded, the insecurities I felt eventually did fade. I guess you could say I had an epiphany after undergoing a double lung transplant when I was 17. I realized that even though I had scars, I also had been given a new lease on life and I didn’t want to waste precious time trying to hide my battle wounds.

These scars show what I have been through and they shouldn’t have been hidden.

It is my hope that the salty girls project will inspire younger girls who are suffering with CF to be proud of their scars. Those who live with CF learn to be fighters, since the disease is something we are up against each and every day. I’ve had learned in my 33 years living with this disease that I am not alone. The greatest lesson I have learned is to reach out and support others who are also living with CF. Together we have hope, together we are strong.”

Kristen

Jennie Reeves Ashe died from Cystic Fibrosis on July 3, just a week shy of her 41st birthday.

(Salty Girls was meant to be raw and powerful, so there was no way to sugarcoat this. Nor do I want to. People need to know the blunt, devastating facts about this disease, without it being glossed over. Just know Jennie will be missed dearly. Below is an excerpt from our last conversation. -Ian)

"I'm forever grateful to be part of such an inspiring project that hopefully changes the way everyone thinks and feels about having a chronic illness. I know this has gotten way bigger than only our imagination thought of....I'm in the process of writing up my thoughts and feelings about CF and being a salty girl....I think it would be easier if I had a pic I thought was "me". You are fantastic at what you do and if the other pics aren't any better than so be it...I kinda feel like I'm on my own in this, don't know any of the other girls but Bailey and I'm kinda old compared to the other girls....lol...anyway....congrats on your huge success with this project. I'm honored to say I know you and am part of all of this....I'm starting to ramble so I'll say bye and I really hope to see more pics.."

Jennie

“What I’ve learned from having Cystic Fibrosis is this: “Normal people” take advantage of everyday life. Contrarily, the people I have met with CF do not take one second for granted. What makes us different is that,

we have a reason to be grateful for every breath we get in this life, because we know we only have a numbered few.

Salty Girls is such an inspirational project that brings a family of kindred spirits closer together. Being a Salty Girl is like being in a large family, where everyone knows what you’re going through. It’s so comforting to know that so many people support you and love you. It’s hard to explain what having a degenerative disease feels like on a daily basis to those “normal people”. But through Salty Girls, I have made countless friends who know exactly what I mean when I say, “breathing has been really hard for me today”. With Cystic Fibrosis, it’s like a community of close-knit friends, and you feel like you know a person so well, even if you’ve only met on Instagram. I cannot express how reassuring it feels to talk to someone else who has my disease. It’s scary going through this life on your own in general, let alone with CF clawing at your lungs with every breath. And yes I have a super supportive family and friend faction that will look after me when I’m sick. But they don’t know what it feels like to have a PICC line, or have your Port accessed, or what it’s like to have the nurses know you by name at the hospital. To be honest, I used to be ashamed of all these things, and not talk about CF much. I would cover up my port, and wear sweaters to cover my stick thin arms. But seeing all these beautiful, inspirational, positive women be unashamed of their bodies and scars and unashamed of their disease brings such joy to my life! The constant coughing, and countless scars can be painful. But truthfully, those are merely characteristics that make me the woman that I am today, and I am nothing less than strong and fearless! I know that being strong and fearless applies to every woman in this project as well. Yes we suffer through pain, but it only makes us more grateful for the happiness we have in our lives. Being a Salty Girl means being able to be yourself, and being happy about it!”

Erin

“To me, Salty Girls is family.
I have never felt such a strong sense of community. Although I have not met 98% of the women who grace these pages alongside me, they make me feel more welcome and loved than I have ever felt. You don’t need a physical presence to connect on a spiritual and emotional level.

Growing up I was the only person in my First Nation community with Cystic Fibrosis. The few friends I’d met through my paediatric clinic were either hours away or died before high school. As I matured, I would listen to my girlfriends complain about their flabby bellies, thick thighs, long noses, etc. and wish that I had those problems. I thought my pot belly, wide flared rib cage, and massive black circles below my eyes were my struggle alone.

When I made it to university, despite liver failure the summer prior, I weighed a whopping 98 pounds. Every inch of me ached. I hadn’t eaten solid food for months. I was morphine dependent. My hair and nails brittle, I coughed up litres of blood, and my bones read like braille beneath translucent yellow skin. It seemed my years were coming to an end.

When I had my port surgery, I saw it as the beginning of the great decline. I assumed things could only get worse. I thought of it as an ugly scar that would ruin my plans to finish tattooing my chest, but I’ve learned to love it. It allows me to take much needed medications and still live a normal life (albeit with an adorable fanny pack). Since being compliant has become easier, my health has stabilized. I am so grateful.

Though I still have my off days, I’ve learned to embrace that signature CF belly! After a lifetime of struggle, I’m maintaining a healthy weight of 120 pounds and I couldn’t be happier about it.

Sitting Bull is attributed with saying, “..The warrior, for us, is one who sacrifices himself for the good of others. His task is to take care of the elderly, the defenseless, those who cannot provide for themselves, and above all, the children, the future of humanity.”

I am honoured and humbled to be among these beautiful warriors as

we fight for awareness and work toward a cure so future generations never know the full horrors of this disease.

While we assure other women - you are not alone and there is always hope and love out there.”

Paulina

“Why do I want to be a salty girl? I was always too thin, bulimic, or anorexic. People have called child services on my friends, cause they thought I was a drug addict and the kids shouldn’t be around me, (yeah the only drugs that keep me alive) as soon as I tell child services I have cystic fibrosis automatically the investigation is over. I want to be part of something that raises awareness for cystic fibrosis. I also want to help someone that deals with the same misunderstandings that I go through, that no matter what you’re beautiful and to keep your head up. When I first got my port I was embarrassed to wear spaghetti strapped tank tops cause you could see the scars and the port sticking out like “hey look at me” I would get asked all the time what is that. I learned to realize that then was my cue to educate what a port is and what cystic fibrosis is. Lately I’ve been having issues with water weight, so I have a barrel belly and little legs. I’ve been asked multiple times “is it a boy or girl?” when I say I’m not pregnant they say, “I’m so sorry but you look it!” So to help raise awareness of cystic fibrosis, why not be a salty girl? All the bruising, all the scars, the clubbing of fingers and toes, all the tubes, and multiple weight fluctuations. That is what makes us who we are! We are a cystic fibrosis/salty girl community that no matter the pain we endure daily, or the pain we go through knowing cystic fibrosis took the life of a loved one or a friend, we support one another to the end. So what is it really like to be a salty girl? It makes me feel more confident in my appearance than what I was before. We all come in different shapes and sizes. We all have the same thing but different stories.

It makes me proud knowing my imperfections are perfect! That no matter what you are sexy and beautiful!”

Joanna

“ When I first met Ian I think it went a little like this… “Hi, I’m Liz! I’m so sorry I’m late!” His response was as if we already knew each other and just said something along the lines of…”No worries, you’re here now! Let’s start.” My next sentence, of course, seemed a bit odd when I blurted out “Yeah, by the way I don’t really like pictures…” Now to be honest, when I heard about The Salty Girls project I thought it would be a good way for me to get over my insecurities about my body and the scars I had obtained. Well let me tell you, that was one of the toughest things I’ve done in my life. If you know me, I’ve been through a lot of tough situations, so you’d think a photo shoot would be as easy as 1, 2, 3. It was definitely not, until I started talking to the other girls and heard their stories. They got me to laugh and open up quickly, which opened my eyes to really understand that’s exactly what Salty Girls is all about; opening up, showing off your battle scars, having confidence in yourself even at your most vulnerable times,

and most of all it showed me to never be afraid of myself and the battles I’ve gone though.

Cystic Fibrosis is a part of me no matter what and although I have a new liver and a new set of lungs, C.F. will always be there. More interestingly, I wouldn’t change the fact that I have it for anything because I have met the most amazing, strong, confident, loving, kind, fun, and BEAUTIFUL people though this tragic illness. The Salty Girls have helped me build my confidence and find inner strength which I didn’t know was there. It may sound crazy that one photo shoot and a few new friends could be so inspirational, but when you see and hear all that we’ve gone through you’ll begin to understand the real beauty in life.”

Liz

“Growing up, I would lie to everyone about my disease, as if I could ignore it away. Scars from two ports, an embarrassing feeding tube incision, and numerous picc lines made me stand out and in return I became a very reserved person. The constant coughing and bright red face was always a head turner. When kids didn’t understand, I became a target for ridicule. Being a teenager is awkward and hard enough on its own, but when you’re the “diseased kid” it can tear you down mentally. I’m short, skinny, barrel chested, pale as a ghost, my fingers are clubbed, and my posture is atrocious. I didn’t fit the mold and became ashamed of my body. People always assume because I’m small, that I must be secure with my body, but that couldn’t be further from the truth. Salty Girls has changed the way I see myself. I do have a disease; I have Cystic Fibrosis and I am still beautiful. My body is different than most and that’s okay. My body may be marked up from years of medication and procedures, it may fail me on most days, but it’s brought me this far and for that I’m grateful. I have fought like hell to keep my body going my entire life and I’m proud of that fact. This is me, take it or leave it. “I’m so far from perfect, so far it’s been worth it”, is tattooed on my arm to remind me of my many imperfections, but also to remember that my struggles got me here.

I don’t need to be ashamed and I am choosing not to be.

Everything I’ve been through in my life, whether it be hospital stays, embarrassing side effects from medications, or causing a scene during a public coughing attack has made for some awkward moments (and amusing stories), but it has also made me who I am. Those experiences have led me to this moment and in this moment I am proud to be in my flawed body. I am proud to show it off. I am proud to be a Salty Girl.”

Cynthia

“Mommy, why are you coughing so much?”

This is what my 6 year old son asks me every time I start coughing. He can tell, just as much as I can, when I'm sick enough to get hospitalized. He is so used to me coughing that he actually falls asleep to it when I put him to bed! I think it's sweet that he is always checking on me. I hate it, though, when I have to tell him that I can't play because I'm having trouble breathing or that I have to stop in the middle of an activity because I start coughing and can't stop. I have spent countless hours thinking about his future and what it would be like if I weren't around.

There have been many people that I knew that have died over the last couple of years and I find myself thinking “why them and not me?” every single time. I came to the conclusion that I'm supposed to do something amazing with my life. I may have really bad days where I can barely breathe or get out of bed, but I still keep going because I am alive and I don't want to sit around wasting the time that I do have. Never let anything hold you back from doing what you want to! Take chances, take risks, and most important be happy because you woke up today and get to make more memories.

I found out about the Salty Girls a year ago and I knew right away that I wanted to be a part of it. Growing up I was never allowed to meet another CFer because of the “6 foot rule” and it sucked. I was lucky to have the support that I did from family and friends, but they didn't know exactly how I felt or what I was going through. Being a part of the Salty Girls has given me the chance to talk to people that are going through the same things I am. I used to think that I was imagining all the issues that my body gives me because the normal healthy people don't have to deal with them. The truth is that I'll always be sick, but what really matters is how you deal with it. My list of medical conditions keeps growing and I have physical, emotional, and mental scars, but I am stronger than you think. Living with cystic fibrosis I have gone through more obstacles than anyone I know, but I won't give up and I will live the best life that I can.”

Carlye

“When I was a preteen, the nurse (who served as our nurse practitioner) at my CF clinic spoke with me privately about my weight. She let me know that I wasn’t just jeopardizing my health by being underweight, but also that I was never going to get a boyfriend. She informed me, “Boys only like girls who have curves.” That night, once my mom and sisters were asleep, I stripped naked and examined my body, desperately seeking this beauty she demanded I achieve. I found the curve of my knees, my elbows, and other places where bones met skin, defining my shape. I did not, however, have a round to my hips. There was hardly anything to pinch on my backside. A girl on my school bus had recently described my chest as “flat enough to take notes on.” I sat on the bathroom floor and cried. I had already been hospitalized two or three times with pneumonia. In that moment I realized, in every aspect of the word, my body was a failure.

Now, I am in my mid-30s, and I want so badly to be able to go back in time and give my preteen self a huge hug and assure her that everything will be okay. She will be loved. There will come a day, after losing many battles while winning her war, when she will look in the mirror and love the skin she’s in – because that is where I am now. After a botched Nissen fundoplication that left me at 72 pounds, two ports, a G-tube, a melanoma that took half of my right breast, a bilateral lung transplant, a kidney transplant, breathing treatments, physical therapy, pancreatitis, endless hospitalizations, intestinal blockages, pain, pulmonary rehabilitation programs, organ rejection, staph infections, bacterial infections, intussusceptions, diabetes, procedure after procedure, epilepsy, handfuls of pills every day, and the experience of watching my friends die while knowing I may go through exactly the same thing, I know my body is my boldness!

What I question now is my legacy. What will I leave behind that will impact this world and make everything I’ve gone through worth it? What do I want to leave behind that really shows who I am and what I believe, while also making a difference in the next generation of young women (and men) with cystic fibrosis? When I read about the Salty Girls Project, I knew it was the answer. I don’t have to question what people will remember me by because I can tell you – right here, right now – and as you read this, you can see my picture and look into my eyes and know I am telling you the truth.

We are a tribe, we are warriors, and we will NOT succumb to the judgment of those who could never manage to walk a mile in our shoes. We are beautiful.

Do not spend your life, not even one second of it, scouring your body looking for a single piece that fits into this puzzle of normalcy. Be bold. Love your scars, love your bones, love your belly. Love yourself.”

Ashley

Erin Phillips died from Cystic Fibrosis on July 21, just a couple of weeks shy of her 31st birthday.

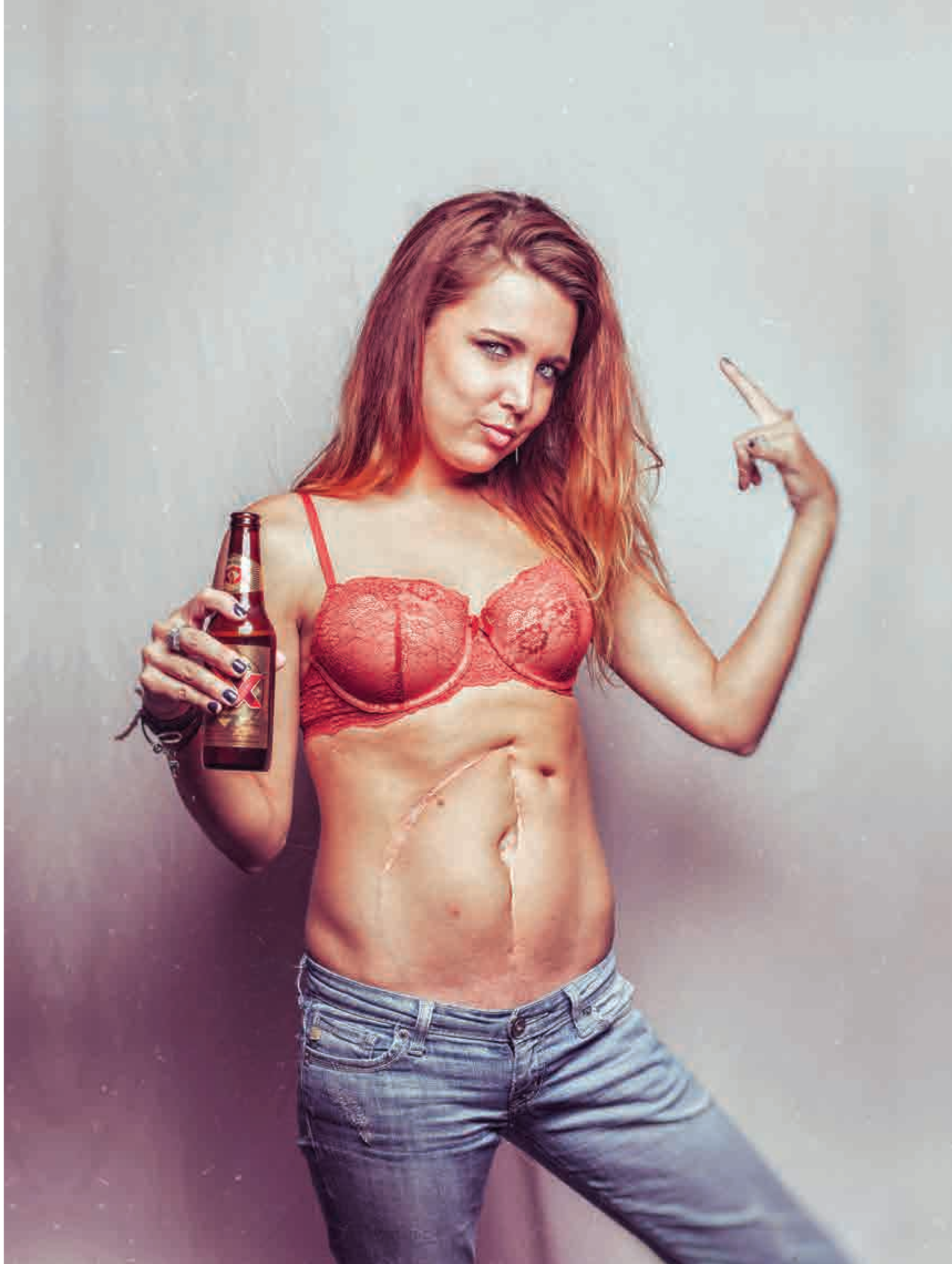
The life of Erin Elizabeth Phillips is one that will be remembered long after her departure from this world. She went to be with her Heavenly Father on July 21, 2015, after suffering a lung infection nearly three years post double lung transplant; she was almost 31 years old.

During Erin's 30 years in this world, she truly embodied what being a CF warrior is all about. She was a fighter from an early age, never letting the status quo limit her or the disease she was born with define her. She was strength and beauty, brilliance and fierceness, personified. Her bigger-than-this-world personality filled a room and left everyone in her path yearning for more of her! From a young age Erin defied the limitations of Cystic Fibrosis, becoming an incredible athlete and achieving whatever she set her mind to in school and sports, including a 1st place title in the 2002 NC Track Championship's 4x4 Relay. In her adult life Erin focused her efforts, energy and time to giving back, working with the charitable foundation More Than Just Me, helping orphans in foreign countries and bringing awareness to Cystic Fibrosis in hopes that a cure may be found. These missions were her heart and her legacy will continue through projects like #TheErinEffect, which will continue her work of bringing hope and happiness to orphans all over the world.

Erin loved the Salty Girls project and was honored to become a member of this illustrious group of women who's scars are their testimony; a testimony that imperfections are beautiful and tell a story of battle and victory over illness. We've been told that many of the women who fill these pages were inspired by Erin's confidence and capacity to put herself out there and also became Salty Girls with a newfound confidence in the beauty of their own battle scars. Though Erin did ultimately succumb to Cystic Fibrosis, her journals tell the story of someone who did not fear death, and knew that God ultimately has a plan for us all. In her writing she noted Psalm 37:5, "God has a reason for allowing things to happen. We may never understand his wisdom but, we simply have to trust his will." Although her time was shorter than her family and loved ones had hoped for, Erin knew God's plan for her life was perfect and used the time she was given in this world to have an incredible impact on others. The scars that she proudly wears in this book, are evidence that she fought hard for and lived her life motto, "Don't be delicate, be vast and brilliant," and she would challenge you to do the same!

The Phillips Family - Jay, Kelley, Kellyn & Jillian

Erin



“I have put off writing this about me blurb for months, not out of laziness but rather embarrassment. I digress, I had hoped I would be forgotten about. It's true, a very large piece of me wished I hadn't pressed on, and been photographed showing the scars that saved my life all those years ago.

But, here I am. Mostly for Erin. Definitely because she exuded confidence that from a distance I envied. I should have told her. I should have made it known that she really helped me feel comfortable in my own skin. I didn't though. Since I didn't then, I damn sure won't go without saying it for anyone who may need to hear it: I am a 32 year old woman who still feels sheepish in any kind of clothing that may show her scars. The truth is, life did this to me. The definition of beauty did this to me. I blame Barbie. Barbie probably did this to me. The irony is, I feel guilty for feeling this way. I feel ashamed for feeling ashamed which turns this into a vicious cycle of humility. I'm alive because of a selfless lifesaving gift, a gift that adorned me with my super spectacular 4-pack and yet I feel embarrassed by it all the same.

I decided to participate in this project for one reason, and one reason only. Not because I exude confidence, but rather I want one little girl or boy who is feeling the way I have felt for the better part of 18-years to see me and say: “Hey, I have those scars too!” I want them to look and maybe for a flicker of a moment not be ashamed, or embarrassed, but to feel whole. To truly believe, and know, that they are just as beautiful or handsome as the person they see on the covers of the Cosmopolitan, or Mens Health magazine. That what makes them beautiful is their soul, not a perfect or imperfect body.

Erin made me feel less alone.

Erin singlehandedly did that for me, and so I'm going to step out of my comfort zone, embrace that these scars are here for the long haul and hopefully give one little mini me or he the same gusto that Erin provided so many of us, and say…Here I am. The scars that adorn me are because my life was saved on November 22, 1997 when one heroic family selflessly donated their 6-month old daughter's organs to a complete stranger, and that stranger was me…and being me, and being reminded of their gift is a pretty incredible thing…and this life, this life is pretty incredible too.”

#THEERINEFFECT

Kasey

“My name is Dahlia and I am 20 years old. I was diagnosed with CF at birth, so I never knew a time when I wasn’t trying to hide my scars. These scars determined everything I bought or wore all of my life. It wasn’t until about two years ago that I started to take some baby steps towards becoming less self conscious about them. Seeing Salty Girls made me want to take that last step. I wanted to be a part of this unique and stunning project, not just for CF awareness, but to help anyone who may be self conscious like I was. Show them it’s okay.

You’re beautiful and amazing no matter what kind of scars you may have.

I have always been a very positive person, so I try to look at CF like a beautiful mess. The “mess” is obvious, but the “beautiful” can be tricky to find sometimes. This project helps to highlight the biggest “beautiful” of all.....Ourselves!”

Dahlia

“ What did I do to deserve this?”

One of the few thoughts that often ran through my head as I tried handling school in my teen years. Walking into classrooms I would hear my peers make rude comments like, “Your coughing is annoying.” The way people were so judgemental made me feel disgusting and ashamed to cough in public.

Becoming an adult, I had people run from me in stores, because I coughed, and they treated me as if I had some fatal, contagious disease. I mean, just because I have a genetic illness does not make me a monster. The way people judged me for years made me anti-social, afraid, and hidden away from anyone that tried getting close. Upon meeting a few others living with Cystic Fibrosis, I noticed that I am not alone in this fight. It helped me gain some confidence back, but when I heard of the Salty Girls, and reading all these amazing stories that these women share, it really touched me and let me come to love my body, inside and out, regardless of my weight and the scars I carry. Because what I’ve been through isn’t weird, it shows the strength I have.

I am a Salty Girl, part of a kick-ass family of gorgeous, strong and amazing girls!
Plus, who doesn’t like a little extra Salt?”

Star

“Broken. Ashamed. Unlovable. Burdensome. Embarrassed. Unworthy. At the core of me, was this voice that echoed these words. These words would weave themselves into every relationship. Few knew just how broken and unlovable I felt because I had this disease. This destroyer was called Cystic Fibrosis. It not only would it wreck my body, but it would seep into my mind and emotions and create great insecurities and fears. For many years of my life, this CF would be my greatest secret. A secret so closely guarded to my heart with only a few who knew how to sneak me off to the hospital in the middle of the night without anyone suspecting a thing. It became scary to share this secret…to bosses, to boyfriends, to new friends…the secrets and fears only increased as the disease progressed and/or the risks magnified.

Empowered. Strong. Tough. Loved. Cared for. Proud. Powerful. Influential. Now at the core of me, is this voice that echoes these new words. When I found running, I found power. I imagined my lungs getting so strong on every run. I kept up with it and started half marathons…even trained for a full marathon. This destroyer of negativity for me was called Running. Eventually my running turned into a movement called OutRUN the Odds or OutRUN38…a powerful force of runners all collectively running, walking, swimming and biking for Cystic Fibrosis. This army of OutRunners is yet another way for me to find the silver lining of this disease. That together we can accomplish anything…including finding a cure. So CF is no longer a secret. It has become the very thing I am proud of fighting….and I fight against it with every bit of my soul. I wouldn't have this fighting spirit if it weren't for my friends, family and OutRUN. People change lives…don't think for a moment that you're own secret or story couldn't change someone else's life. In fact, the other Salty Girls stories changed my life and they didn't even know it.

When I took this picture for Salty Girls, I didn't have my dexcom on my stomach for my diabetes. And I didn't have my feeding tube placed yet. In fact, that voice that echoed “broken, shame, unlovable, unworthy, gross” and all those negative vibrations crept back in the mind. That voice was the voice that would keep telling the doctors for two years “no thank you” to the feeding tube…but they kept insisting I needed it. I didn't want yet another reminder of this disease…

BUT THEN... I started seeing the other Salty Girls look so fierce, strong, chic, hot, and just own it!

Tubes, scars, marks, oxygen tanks…they owned it! It was actually being a part of Salty Girls that allowed me to face my own demons and say “Yes, It's time for the feeding tube.” If they could carry these scars and feeding tubes and look so bad ass, well damn it, I could too! So I owe my own Salty Girls a huge thanks…I wouldn't have found the courage to get my feeding tube and be in more control of my Cystic Fibrosis if it weren't for you. I couldn't be prouder to be a Salty Girl! I can only hope that other CFers will see this and follow suit…and do whatever it takes to take ownership of your disease with your head held high and feel proud of your battle wounds.

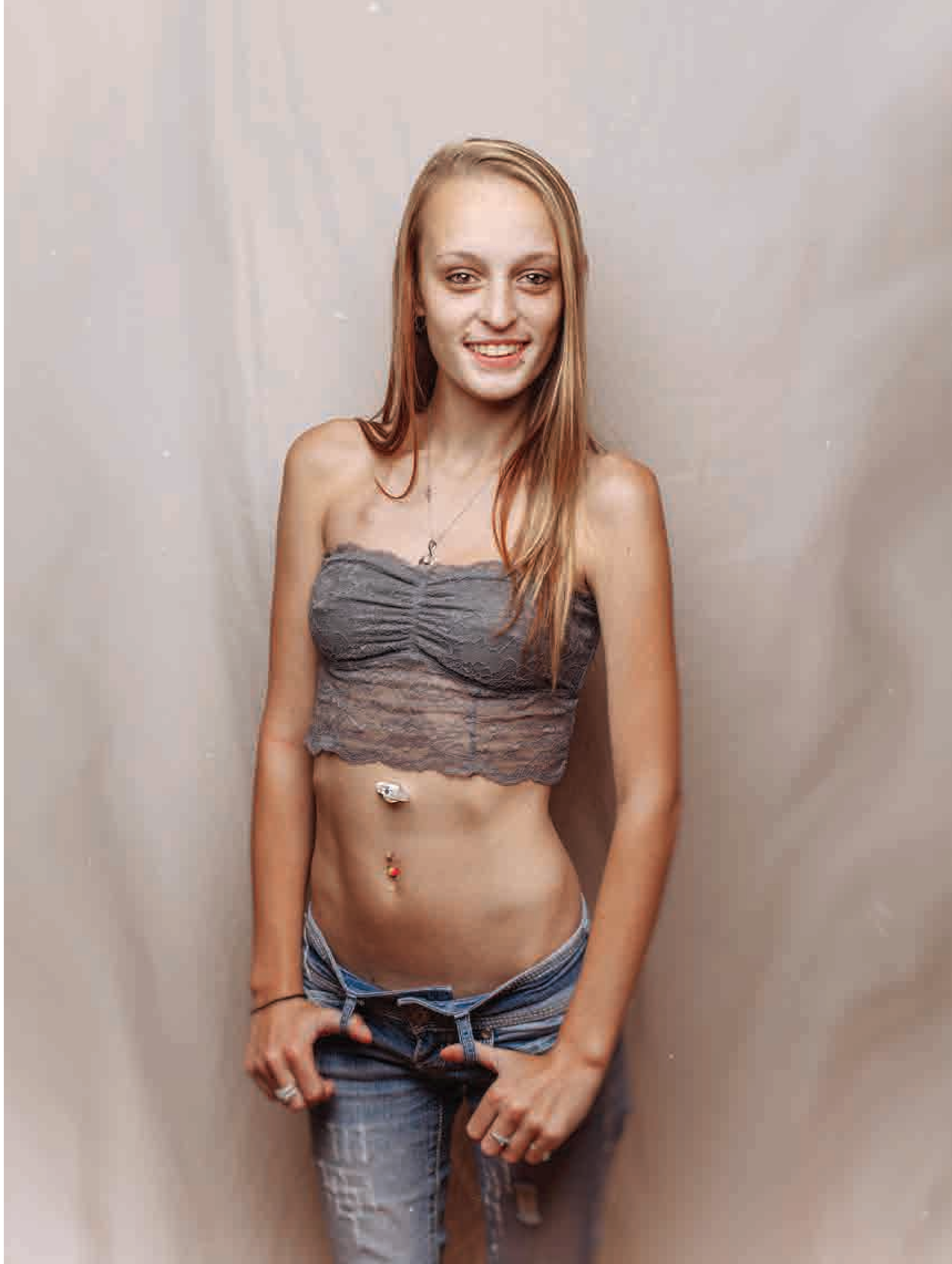
Rock On Salty Girls… Rock on!! WE GOT THIS! FUCF!
We Shall Overcome”

Liz

“ But you don’t look sick...”

This disease is a curse in disguise. People look at you and think you’re doing good but inside you’re not. The physical appearance don’t mean anything. If my body was flipped inside out, it would be ugly. Growing up I always tried to hide all the scars, terrible cough attacks, the pills and treatments just to keep people from knowing I was sick. I felt like I had to hide apart of my life in a box just to fit in with the crowd. After I heard about the salty girls project and what it stood for, I instantly knew I wanted to be apart of it. I wanted people to finally see who I was and not what this disease portrayed me to be. What the project has meant to me; finally I was able to feel beautiful and not so alone. Now I know there are others out there just like me. I feel more alive and accepted. Stepping out of my comfort zone and showing my body with its flaws and scars, finally being me and showing the positive side in having this terrible disease. Yeah, I may have CF, but I am beautiful and sexy just like everyone else.”

Stormi



“ You’re like a ticking time bomb.”

So, I am writing to tell you all about a life with CF and Transplant. I could tell you about the endless rounds of physio, the mountains of medication, the time-sapping regimes of nebulisers and the moral-sapping stays in hospital every few months. I could talk to you about the fear that comes with waking up in the morning and not being able to take a proper breath in. Unable to walk or run up a flight of stairs without stopping halfway for a 5 minute break to get my breath back. I could talk about how I had no idea if I’ll make my next birthday or let alone wedding day. I could talk to you about how I couldn’t even pick up kiddies/nieces/nephews anymore. I can talk to you about all the blood I have thrown up, litres and litres of blood all over floor. Or, I could talk about the difference liver and a double lung transplant has made to my life, difference is I lived. These are all things I could tell you about, if I had the time. Liver Transplant 2006, Double Lung Transplant 2014. Welcome to the new world.

Instead, let me put this to you: imagine, for a moment, you suffered from a disease where you knew that transplant was your last – and only – option. Imagine being forced to communicate with friends solely through the internet because you can’t be in the same room. Imagine the isolation and the fear and then imagine seeing your friends, slowly but surely, die from the very same thing that is destined to kill you.

That is the reality of a life on the transplant list. It’s a life on pause. That is the reality of day-to-day life with CF: no let-up, no respite, no days off. Just 24/7/365 fear, pain and often despair, mixed with hope, belief and often, a bit of a giggle – we’re known for our dark senses of humour.

I wanted to do Salty Girls to make people aware what we go through, and bring awarness in, be apart of something so amazing with a great group of warriors. It means everything to be apart of this and speading the word world wide, with pride and joy. I hope whoever sees this can understand what we are going through, we may look like simple people but deep down, we are in prison with ourselfs. Everyone’s scars tell a story, that you tell over and over with pride.

“My life was on pause. It isn’t anymore! People said I was a ticking time bomb. Now I’m just da bomb haha.”

Kaela

“I was diagnosed with Cystic Fibrosis at three months old and had a gastrostomy tube placed at eleven months that saved my life. I grew up with nightly tube feedings, breathing treatments, physical therapy, and a plethora of medications being normal. For a long time I didn't realize how different I was, I knew nothing else.

Until I was seven. For the first time I wore a two-piece swim suit to the beach. I remember that day vividly - building sandcastles, swimming, playing at the park, spending time with my family and making new friends. I was taking a break from all the fun to have a snack, when two girls about the same age as me asked my sister if she wanted to go for a walk with them. My sister and I got up to go with them and one of the girls looked at me and said “No, not you.” That didn't faze me; I had my little brother to play with anyways, so I sat back down.

A few minutes later, my mom was rushing to my sister and the girls, trying to stop my sister from attacking one of them. After my sister was calmed down we found out what triggered her anger. When she asked the girls why I couldn't tag along, one said “Why would we want to hang out with her? She looks like a blow up toy.”

I remember that moment every time my stomach is exposed, even though now only a scar is left. Nobody should have to be discriminated against for having a medical condition, or a life-saving piece of medical equipment. By suffering from a chronic illness, like Cystic Fibrosis, we face criticism daily. We can't always hide our disease because the scars, equipment, constant coughing and exhaustion give it away.

But we shouldn't feel like we need to hide.

Society needs to be more accepting; most people don't fit their idea of “perfect.” When I heard about Salty Girls, I knew I needed to be a part of it; empowering women and raising awareness for Cystic Fibrosis. Most importantly, it helped me realize that we are all beautiful and our scars do not define us.”

Sarah

“ Sexy isn’t about what size you are. Sexy isn’t about how perfect your smile is. It doesn’t mean that you get 10 numbers everytime you are at a bar. It doesn’t mean you don’t have any flaws. Sexy is all about the scars and the strength behind them.

Sexy is being comfortable in your own skin.

It’s embracing your body, mind, scars, struggles and love. Being a Salty Girl is being apart of a family through CF. It’s knowing we share so many things together and not all of them CF related. Being a Salty Girl is being an advocate for hope, awareness and acceptance. We also differ in vast ways from location, culture, looks, age, mutations, personalities etc. We struggle. We fight. We love. We live. I am proud to be a Salty Girl and feel that it is an honor to be part of this “CF society” that is showing the world we are here! CF is real! We are flesh and blood, bones and heart, lungs and voices. Being sexy is just part of what makes us human. We are badass beautiful chronic fighters. Every cyster is a Salty Girl! The saltier the better. I will always sprinkle that saltiness everywhere. Be proud of yourselves for putting yourself out there. I am. I couldn’t be happier and more grateful to be apart of this adventure. Love and Light! xoxo”

Nina

“ Four years ago, I was literally lying on my death bed at a UK hospital.

I was ready. I had made my peace with God and was simply exhausted from the fight. I was in the process of telling my mother goodbye, amidst a vortex of tears and prayers when my transplant coordinator entered the room to tell me that they had new lungs for me. It was a miracle. It was a last-minute death row pardon. And yet, when the surgeon came in to explain the details of the surgery to me, one of my main questions was: How big will the scar be? He looked at me like I was insane. Don’t get me wrong, I was indescribably grateful. I just wanted to be prepared. I’ve never been one to blame my problems on society in general, but I think we can all agree that women are pressured more than ever to have flawless bodies. The double-standard is ridiculous: Men seem to be at peace with their scars, proudly displaying them to friends and family, with detailed stories about how they were acquired. They symbolize toughness, courage and, ultimately, survival. Yet as women, we tend to hide ours. Too many of us associate our scars with imperfection, inferiority, and shame. Women with cystic fibrosis face the double-challenge of trying to uphold societal standards of beauty, all the while having no choice but to surrender to countless life-saving surgeries and procedures that wreak havoc on our bodies. For me, the Salty Girls project was about spreading awareness to others about the battles we fight behind closed doors, while at the same time encouraging women with CF to look at their scars in a whole new light. Not only did it inspire me to be proud of my scars and all they symbolize, but it gave me the opportunity to meet so many amazing, confident women with their own battle scars, both physical and emotional. Our bodies are living canvasses of strength, bravery and resilience. How can that be anything but beautiful?”

Crystal

“All of my life my body has been such a disappointment. CF has made everything such a challenge; It makes anything simple a chore.

The salty girls project was a great experience for me. It brought me close to others who suffered the same issues I have my entire life. We came together and drew strength from each other. This was One of the most profound experiences in my life. It has helped me stand proud and feel good about this body that has been nothing but a huge let down in so many ways.

My hope is that other women can also gain strength from this project and love the skin their in and enjoy life to the fullest.

No matter how we perceive ourselves, we are beautiful, we are strong. We only live once so don’t waste a minute fretting about those scars, embrace them like the warrior you are!

I’d like to thank all who have always been there for me in my life and time of need, My family. The most important thank you goes to my husband and daughter, for it is they who keep me pushing for more time on this earth through all the procedures and hospital stays. I’d also like to thank my angel on this earth, Rachele, for carrying my child for me, when my body was not able to do it, and for the future child we will bring into this world.

Last, but definitely not least, I’d like to thank David, who helped me gather the info I needed to fight for Kalydeco off label. Without Kalydeco, I would have been transplanted by now or be dead.

I love my CF family and all my Salty sisters. May you all stay healthy and happy until CF stands for cure found. Live long, love hard and be bigger than yourself.”

Rebecca

“ The older I get the more my body amazes me.

(I am forty three). We all have a capacity to heal that astounds me. I have had many surgery’s (including double lung in 1999) and I carry many, many scars.

I stand and I walk, live and breathe in this little body that happens to have a genetic mutation called Cystic Fibrosis. I used to worry as a younger woman about my skinniness, my clubbed fingers, my scars.

Now, I look at my body in gratitude and amazement. I breathe with another woman’s beautiful lungs and have for almost 16 years. I have born and cared for two children with these capable hands, often with IV’s attached.

I think as women we all should worry less about the size and shape of the bodies we reside in and appreciate, care for and enjoy our physical beings more.

Our bodies respond to love and care and joy. With them we work and breathe and give to those we care for. This is beauty.

I hope this book inspires girls of all shapes and sizes, with illnesses or without, to be proud and unashamed.”

Fiona

“Doing the “Just Breathe” project for adults living with Cystic Fibrosis was a very empowering experience. Being able to give CF a name, a face, a story, a life and major recognition was absolutely amazing! When talking about the Salty Girls idea, it sounded like a lot of fun but little did I know how empowering it would be and in a whole new way!

All my life I have had insecurities with my body, as most women do, and a bloating belly was definintely not considered sexy. It didn’t look sexy and it definintely didn’t feel sexy! I have been asked if i’m pregnant by random strangers on many occasions, asked if I smoke because of my raspy voice, asked why I am always sick or given looks of disbelief if people do not know my condition, I have been in and out of the hospital for constipation and lung issues, I have hated looking in the mirror at how I look in clothes and question if I would be given looks by others, Not only was I ashamed of my body on the outside, it was harming me on the inside as well and I was beginning to hate myslef. At times I have felt that no one would find me sexy. Why would anyone find someone sexy and beautiful with a belly that, at times, makes them look pregnant, who may not look amazing in a bathing suit, who coughs a lot, who is in pain a lot and deals with a chronic illness that will never go away and is so unpredicatable?! Who would sign up for all this?!

Then “Salty Girls” became reality and I was asked to be apart of this amazing project! I felt honoured to be asked. I knew I wanted to portray an image that was sexy, classy and mysterious all at the same time and to me a woman in a man’s dress shirt was just the way to do this! **During the photoshoot something took over in me...**

it was called
self confidence,
power, strength,
courage, trust
and sexiness!

I had the stregnth and the courage to do a photoshoot like this and put aside my negative self image and thoughts. I had self esteem! I trusted in my photographer and in my decisions. I felt sexy and beautiful in a healthy and positive way! CF did not have a hold of my self image or my body in that moment.. or even afterwards! Everytime I feel those negative self images or thoughts coming back, I look at those photos and I feel beautiful, strong, sexy and empowered all over again!”

Steph

“A road map is what is see when I look in the mirror. Scars from all the surgeries, tubes, and implants that I have ever needed to stay alive. I used to be embarrassed to be in a bathing suit or to wear something skimpy. Now I embrace myself. I know that my scars or as I like to call them “ my war wounds “ are why I'm here today. I have had over 6 sinus surgeries, abdominal surgery more than twice, a double lung transplant, and not to mention here and there procedures.

I have always had a CF belly. I've been asked several times if I was pregnant. NO! I thought I was the only girl that looked pregnant all the time. HA HA. But seeing and getting to meet all these other Salty Girls, I have read and understood their problems are the same as mine. And that's what I love about this book! Not only does it show people without CF, what we are all about,

it helps other CF women understand that they are not alone.

So I am here today writing to let you all know...I've got SCARS, I've got a BELLY, and I've got CLUBBED FINGERS! I AM BEAUTIFUL!!!”

Kristen

"To be honest, part of the reason I didn't get a g-tube placed sooner than I did is because I was scared of how it would make me look. I was already using oxygen which drew in enough attention as it is and I didn't want anything else that might make people stare at me. That may sound petty, but for a 24 year old girl, having a tube sticking out of your stomach is a pretty big deal. As it turns out Cystic Fibrosis isn't always an invisible illness; barrel chests, oxygen tanks, scars from surgeries, needles, and transplants are sometimes painfully obvious. It's hard to feel sexy when I'm hooked up to so many tubes and machines. Yet, while I'm thankful to have friends, family, and a boyfriend who accept everything about me,

I realized that self-acceptance matters most of all.

Becoming a Salty Girl has not only helped me to accept myself, but also makes me feel like a stronger woman. One who doesn't (and didn't) let anything hold her back. I realized these scars and tubes deserve to be celebrated. After all, they are the reason I'm still alive. Being a part of this project has given me an opportunity to stand up and be proud of my scars and to show other people that they can stand up and be proud of their scars too, because now they won't be standing alone."

Rachel

“I remember when I heard about the Salty Girls Project. It was a couple days before my Just Breathe Project photo shoot, and while I adored the idea, I didn’t yet know the photographer, Ian, and I wasn’t comfortable enough to have my photo taken in my bathing suit. Honestly, I wasn’t sure until I was at my photo shoot in Daytona whether or not I had the courage to pose. But I did it. I was so proud and excited for the whole project. I felt empowered and as if I could single-handedly help women everywhere feel more comfortable in their own skins. Then I saw my photos online, and I was crushed.

When Salty Girls first started going viral, I was over the moon. As excited as I was about this going viral, I was super glad I didn’t appear heavily in it. I was part of the project and proud of the project, but I am going to be very honest and open in saying I hated the photo of me that was on the Salty Girls website. It has nothing to do with the photography - if it were a photo of someone else I would say she’s gorgeous and brave and all the things people have said about me. I hated that photo because of my own insecurities about my body.

When I looked at that photo, I kept telling myself it’s not so bad. When I remembered the photo in my mind, I saw an extremely overweight, ugly person. I couldn’t get the phrase “thighs like a hippo” out of my brain. I would gather my courage and go back and look at the photo again, and see it wasn’t as bad as I remembered. Rinse and repeat. This went on and I ended up having a panic attack even if I thought about my image on the website. I knew I had to have Ian post a photo I was more okay with.

Eventually I did ask Ian to find a photo I was more okay with and post that on the website and in the book instead. He was very kind about the whole thing. I’ve thought about this project a lot in the last year. I’ve thought about my body image a lot in the last year. I don’t *LOVE* the photo of me that was chosen for the website and the book, but it’s who I am. It’s me showing the world what a woman with CF looks like.

It’s me showing the world we’re all different and beautiful in our own ways.

When I was in college I got to as low as 115 lbs. I never want to weigh that again. That comes with its own issues and insecurities and frankly, it’s a pain in the ass to be underweight. I know being a little overweight with CF is a blessing. But knowing that doesn’t make me love the way my body looks.

I know that being part of this project will help show there are women with CF who are overweight. And that’s okay. That’s why I wanted to do the project. And hopefully it will, in time, help me be okay with my body the way it is. This project has been and continues to be such an amazing experience. It’s empowering, and I know it’s doing good and showing women that they are beautiful no matter what they are struggling with. And as a HUGE bonus, I’ve made some amazing friends and met some seriously inspiring women!!! In this horrible, terrible disease there are beautiful people trapped. There is beauty in this fight.”

Carla

“Growing up I was faced with situations any normal child would never even imagine dealing with. I was asked questions like “Why are you so skinny?” or “Are you sick, you keep coughing?” In my eyes I was normal. I was born was Cystic Fibrosis so it was all I ever knew. Doing daily treatments and eating high caloric meals was just part of my normal routine. Being a member of the dance team in high school made me feel like a normal girl with a big secret. I didn’t tell anyone about my disease. I blended in and felt like I finally belonged.

After 2 double lung transplants, I started to embrace what has happened to me. I had a second and a third chance at life and I wanted to make the most out of it. When I encountered “Salty Girls” I knew I wanted to be a part of this revolution. Glorifying the beauty of what lies beneath such an evil disease has been long overdue. Seeing the faces of Cystic fibrosis is a breath of fresh air and the confidence beaming from everyone’s face is exuberant. I am now part of a group that understands who I am and where I came from.

I get to embark on a new journey with some extraordinary girls **who know exactly what it’s like to live with Cystic Fibrosis.** A place where we can be ourselves and not be ashamed of how we look and how many scars cover our bodies. It’s a time to embrace our stories and share them with the world. Being a Salty Girl.”

Cassie

“My name is Amy Lee, and I am a chronically sarcastic, sugar-addicted, caffeine craving, and adventure-loving teacher. I spend my days playing with glitter, crayons, and somewhat germy kiddos all while battling an incurable disease that has left me with some pretty badass scars.

On more than one occasion, I’ve been asked “How do you have so much self confidence?” by people who seem unable to fathom what it might be like to live in a body covered in scars and marks. I always found that a tricky question to tackle because the answer isn’t a simple one. Yet, if I could go back to all of those moments and give a solid answer, it would be this:
It wasn’t just magically stuck in my brain one morning when I woke up. My confidence has been a long time in the making. I’ve spent years of my life riddled with insecurity and doubt. I’ve looked for validation in all the wrong places. Although I still have moments of uncertainty,

I have come to the earth-shattering realization that I am the deciding factor in how I feel each day.

I can whole-heartedly promise you that I love every single millisecond of my life. Sure, I might not fall into society’s definition of “beauty” but I don’t love myself any less. My heart and my passions are the most beautiful parts about me.”

Amy

“I have Delta F508/G551D, a classic combination of CF gene mutations. I’m 36 years old and am setting new intention and goals for the next half of my life, as I have, incredibly, fulfilled all of my life goals to date. I managed a balance of sports, academia, CF therapy and social life throughout high school, earned a bachelor’s degree from a top university, married a great guy and naturally conceived, and carried to 40 weeks, delivering a healthy baby boy. Prior to motherhood, I had an exciting 7 year management level career in product design. Now, I am inspiring others through wellness coaching and through my client’s successes, I’m finding new inspiration. It’s true that only in lifting others up shall you rise.

> I absolutely love who I am today and can’t wait to see where I go with life tomorrow.

I don’t consider myself a victim, but undeniably cystic fibrosis has infiltrated and affected every aspect of my life. It doesn’t define me, yet it has influenced me to be focused, determined and disciplined. Approximately 50% of my waking hours are dedicated to a cystic fibrosis related task of one sort or another. Management of CF is a full time job, with therapies, cleaning equipment, scheduling appointments, insurance, bills, etc. In fact, they’ve got an app for that, called Tonic, and it’s based on my life. I pump up the volume, both literally and figuratively, to drown out the sound of my coughing, wheezing, crackles, raspy voice, panting and throat clearing as I engage life. While I realize I can’t run from CF, I have always rushed to fit it all in. Sprinting towards my goals, a big part of my success in the last 7 years is intrepidly getting lost in the adventure of life, while micro-managing the unpredictable flow of cystic fibrosis.

I’m intensely engaged in everything I do from childrearing to fundraising to advancing CF care. I’ve participated in the clinical trials to bring Kalydeco to market. It was a physical and emotional rollercoaster of placebos and progress, and to-date my biggest life achievement since my son. Participation in Salty Girls was perfectly timed in my life. It’s been almost 3 years to the day since I embraced management of my CF through nutrition and exercise realizing that medication was not the only answer. I changed my body composition to be more muscular by feeding it quality, macronutrient food which has helped me to be more resilient and has increased my athletic endurance. I continue actively engaging in all that life has to offer. I’m beginning another clinical trial, running a half-marathon with my CF MD, focusing on the love of my family, and always reminding myself to just breathe. I’m optimistic that I WILL LIVE to finally use that retirement account Dad keeps telling me to fill! Love you, Mom & Dad!”

Lauren

“I am Meranda and I am a proud 32 year old Salty Girl! I have been through significant health challenges throughout my journey with CF. I dedicate most of my time to my breathing treatments, vest therapy, oral and intravenous medications. I continue to push forward despite the obstacles I must overcome due to complex health complications. This resilience is evident throughout the CF community, and especially within the “Salty Girls” group!

I spent my 20s struggling with insecurities, feeling inadequate and with my self-esteem being nearly non-existent. My health began to go into a sharp decline in my late 20s despite me doing everything possible to stay well. It was during this time I relied upon my incredible support system which included close friends who also have CF. A few of these close friends are fellow Salty Girls also photographed by Ian Pettigrew!

When I turned 30 years old I was given the opportunity to participate in a clinical trial which stabilized my health. I embarked on a new journey in life determined to make the best of each day as if it were a gift. I met Ian Pettigrew at 31 and decided to tackle my shyness to show the world I am proud to be a Salty Girl. I am now 32 and believe my future, thanks to research advancements, is looking better than ever!

I am proud of the woman I have become and look forward to each day!

When I look in the mirror today I see a strong, resilient, compassionate and passionate woman determined to make a difference in the CF community! My genetics may be imperfect but I love the woman I am today!”

Meranda

“The Roman poet Phaedrus wrote, “Things are not always what they seem; the first appearance deceives many.” Cystic Fibrosis (CF) is often considered an invisible illness. I've always considered myself to be blessed with having a milder form of CF. The most visible part of my CF is my cough. Although my cough keeps me alive, I often suppress it to avoid the attention it brings. If you've heard the “CF cough,” you know it and remember it. Imagine a moist, wheezy duck honk that produces various colors and textures of phlegm. Not pretty. This gooey, continuous infection is why I do treatments that help my lungs stay clear.

Learning to deal with the emotional issues that come with having a chronic health condition has been more challenging as I get older. It's difficult for me to not compare my accomplishments to those of my peers. I tend to think, “Everyone has their challenges. So why can't I keep pushing forward to meet the same goals others have?” I realize that I must be more realistic and continue to value who I am. It's not easy admitting weakness. But I refuse to let CF take away my ambition to succeed and live a quality life.

I have a hard time admitting how much CF takes out of me. My energy is currently a huge hindrance and it feels disingenuous putting up a front. I want to work full-time, go on vacations and camping trips, and have the energy to hang out with friends every once in a while. I'm happy that I CAN actually do many of these things, but then there's the recovery that most people don't know about. Being exhausted seems like my way of life. For instance, I can show up to work and have a productive day (with a smile). However, when I get home, I am done. Cooked. I do my best to stay compliant with my therapies and even attempt to work out on some days. I dig deep and look for whatever motivation I can find. Most recently, Wendy Duran has been my accountability buddy. She is one of my online “salty” friends and has helped motivate me to stay on track. I have also been inspired by Christine Miserandino's story, The Spoon Theory, which inspired me to be more realistic with my energy and daily activities.

It may take up to a week to completely recover from a weekend camping trip. Despite the toll it takes on my body, it is so worth it to me. Admitting fatigue to friends and family feels like complaining. I don't want people to feel sorry for me and figure out that I'm not as strong as they believe I am - it makes me feel defeated. At times, I feel like I need to wear a fake smile and pretend I'm a “normie”.

The Salty Girls project is helping me work toward living a more “real” life

- fewer fake smiles, being more honest with people who care, being realistic about my energy, and learning to accept my accomplishments as true achievements.

My photo shoot for this project is also a personal analogy: CF as an invisible illness. At first glance, it appears that I am simply wearing a scarf. The pose and revealing nature of this photo is so far out of my comfort zone even though I am actually wearing a tank top and shorts underneath the scarf. It is an example of how my confidence has increased and that I have people who are there for me. My husband, Scott, was there to support me. My friend, Tanya, guided me through poses and much more. Ian did his thing and created another fabulous photo! I am really happy I did it and hope to inspire others.”

“Be who you are and say what you feel, because those who mind
don't matter and those who matter don't mind.”
~ Dr. Seuss

Wendy

“I have had months upon months to do my part and write my blurb for this life-changing project that I am so humbled to be apart of. I’m hoping with the words I say here that you believe them. That you please read them with an open mind and open heart. As I’m sure most of you know I’m one of the last to get my blurb done if not the very last one to be very honest with you all. After I did my shoot for this project I felt like I was on cloud nine. I felt beautiful for the first time with this disease. I didn’t feel alone anymore. I have been very fortunate in my life with CF and I haven’t had not one surgery. So with that being said I don’t have many scars or things to show that I have gone through things in my life that people shouldn’t have to go through on a regular basis or in there life at all. But like I said I have been very blessed and fortunate to have the life and health that I have had thus far. I know so many absolutely incredible people in my life whether they have CF or not that have things far worse than myself. Every time I went to write my blurb I completely broke down. I started to a while ago after my second mama passed away. Someone I went to for anything and everything in my life. So I tried and couldn’t get through it. So I waited for some time and I decided to wait until I got back from Daytona to write it. Well I landed myself in the hospital right after Daytona so I thought no better time to write it then while in lock up. Nothing but time on my hands in there. Well almost one week into my stay I get a call from my father saying my older sister has taken a turn for the worse. I went completely numb in that moment and to be honest for quite some time after. I got out five days later on a Friday and my sister was still holding on. The next day Saturday, she passed away with me and my family by her side. Nobody in my life loved me and cared for me more or like my sister did. So after some time after her passing I went to write this again I started sobbing and completely broke down once again. So I put it away I was thinking about things way to much. So recently went to write it and all I could think about was my beautiful best friend that was in the ICU at the time. This last time I went to write this was recently in the hospital after getting back from North Carolina visiting my girl. I got a phone call saying my best friend had passed away. At that point I was just done to be truly honest with you I didn’t even know if I should even do my blurb or be apart of this project any longer. After really thinking and praying about everything asking God to help me and asking all of my beautiful angels to please help me write this. It would be very selfish of me to just give up on this, on everyone and on Ian who has spent an abundance of time and money into such a beautiful beautiful blessing of a project. So with the help of many, here is my blurb finally. What I really hope and want people to take away from this is to never judge a book by it’s cover. What do I mean by this well by looking at me you would never think that I have a lung disease or any other struggles that come along with it. You would never know that my sister had anything until you would see her seize or see that she couldn’t walk and had to be in a wheelchair. You would never know that my second mama had cancer until she started losing her hair. You would never know that Erin had CF until you saw her scars.

One of my dreams is to help people all over the world.

To change the world. To open peoples eyes that disabilities are all ages, sizes, and so much more than just something that you can see on the outside. Everyone has a story that you know nothing about. That smile that you gave. That I love you that you said. That hug you gave. That call you made. The prayer you said. The trip you took. That person you helped on the street. That time you died to yourself to forgive someone. That life that you changed forever by doing one of these things. Who knows you could have even saved there life. These women and all of my cysters inspire me every day of my life to keep fighting. Every breathing treatment, vest session, pill I take, hospital stay, test, doctors appointment, workout, and so much more I do for all of you. Let’s build each other up and be an example to so many that having something that is different than others it’s ok. That you can be proud to be in your own skin. To be an example and show people that there is such a thing as an invisible disability. To never judge a book by its cover. I believe this book will change lives all over the world. This is something I know I have been waiting for for a very long time and I think I can speak for a lot of us when I say that. My passion and drive to help others is unexplainable. I want to lead by example and hope along the way that I can inspire people to be themselves, to be happy, to be kind, to help others, to take care of themselves, to love deeply and to never take a single breath for granted.”

Sophia

“ I don’t know how you do it. I know I couldn’t.”

I hear this often from people in my life, at one time or another. Mostly it’s from acquaintances, sometimes from family or friends. But the truth is, if you had cystic fibrosis, you would learn to deal with it. Some days you would deal with it poorly; others you would kick your own butt to keep going. You would do every single thing needed to stay and feel healthy.

During high school, my CF was getting at its worse. The reason I was getting so sick was because I had developed cystic fibrosis related diabetes. I was actually ashamed of having cystic fibrosis. I wouldn’t tell anyone about it, except for my really close friends. Pity was the last thing I wanted. At that time, I did not realize that it was compassion reflecting through their eyes and not pity. Once I decided to be honest and open about my CF, I felt liberated and I got a little bit more control over my own life.

I wanted to do Salty Girls because I wanted to be part of something that I knew would change how people would see cystic fibrosis. While feeling more beautiful in the process. My dream is that one day when coughing out in public, someone would ask me if I have a cold and I would simply reply: “No, I have cystic fibrosis.” Then, they will tell me to keep on coughing, because they would understand that I am not contagious and that coughing is good for me. They would know the importance of coughing for someone with CF. Also, we are like everyone else. We have hopes and dreams, but having cystic fibrosis sometimes means modifying those dreams because your body can’t keep up. It means to slow down and think through everything you do because your health might suffer. It means working ten times harder just to achieve some kind of normalcy. What people need to know about cystic fibrosis is that it does not mean giving up. It means to keep on going, even when you can barely breathe and your body has a difficult time listening. It’s starting over every time you get a lung infection. It’s to be perseverant and resilient.”

Katrine

“This raw exposure is very out of character for me. I have spent half my life hiding from this disease and the other half running from it. Death started stalking me when I was eight years old in the form of a complete intestinal obstruction and resulting complications from a risky surgery. The CF diagnosis and associated struggles came next. What I was not prepared for with this disease is the resulting insecurity.

It’s not just the scars. It’s the comments and stares when I have a coughing fit in public. It’s the worrying about being a burden, not being able to keep up, and holding others back. It’s the fear of being left alone. It’s the depression and anxiety and isolation of living with this death sentence hanging over my head. There have been days where it seemed easier to give up and welcome Death who is so patiently waiting for me just around the corner. The emotional struggle is just as real as the physical struggle.

Being a Salty Girl to me means standing up to the insecurities this disease has bred in me. I’m tired of hiding. CF has been slowly destroying every part of me. Being a Salty Girl is helping me gain the confidence to get some of myself back. My scars are very small reminders of the battle I am fighting on the inside.

The battle rages on, but for the moment, I feel like I might be winning.”

Adrienne

“I hid my disease for years, decades even. I was so embarrassed to open up and tell people that I have Cystic Fibrosis. Even though it is not contagious, I still held on to that feeling of acceptance. Why would someone want to be friends with a person who gets sick easily thanks to a terrible immune system and coughs all the time.

That’s where this project has opened my eyes to see the better in people than I ever did before. Over the past five years, I’ve opened my heart and invited people to understand what it is like to live with Cystic Fibrosis. Opening up has shown me that there are people who care. Yes, I’ll be 30 in a couple years -- I’ve wasted a lot of time hiding CF. This project has helped me connect with more CF patients via social media than I ever thought was possible. I can jump on social media, message a fellow CFer and talk with them about how I’ve been feeling. Maybe I’m having a problem with my feeding tube or noticed something with my PICC line and IV injections. I’m finally connecting with people just like me. I didn’t have that growing up. The kids I grew up with didn’t understand what my life was like; why my skin was different, why I coughed all the time, or why I always had to take medicine before I ate. They said very hurtful things. Once, I had someone throw an open bottle of lotion on me on my way home from school because I had dry skin. I look back at incidents like that and I believe it was because those people were ignorant. Part of that is my fault, I wish I had felt more comfortable in my body earlier on in my life.

I know that this project is influential. I am no longer afraid to wear a bikini that shows my feeding tube.

It took me a long time to realize that it doesn’t matter what other people think of my tubes and scars.

I walk around with my IV line in my arm when I’m sick and I don’t care who stares. You can see the wheels turning in onlookers’ heads making up a million reasons for why I have a tube coming out of my arm. I smile, it’s what this disease has taught me how to do best.

I cough often. I still catch myself feeling uneasy about that. And then I remember - no one is perfect. There are so many people like me. We will fight this disease. We will bring awareness to Cystic Fibrosis. I pray every day for a cure. I know it will happen. When it does, I’ll be ready for it, scars and all.”

Gabby

“Battling your own body on a daily basis isn’t the easiest thing to do, feeling hopeless and broken underneath looking normal. It’s the feeling in itself of knowing you may never have a child of your own or even live old enough to marry. It’s a monster of a disease and claims so many beautiful lives way too soon. It’s the feeling of not wanting to wear a swim suit because you feel so uncomfortable with all your scars and all your ribs showing. CF is many shitty feelings combined into one word, one disease. Before the Salty Girls project, I never felt comfortable just letting my scars show. I never would wear a two piece in public even though I was only 100 pounds. It gave me the confidence to feel sexy and feel like a normal girl for the first time in 24 years.

I spent YEARS hiding scars, hiding coughs, and hiding my whole life story just to fit in to society.

The many years I’ve spent dealing with harsh comments about anorexia or the dirty looks from coughing and people thinking I’m spreading a plague. Society can be so cruel but we shouldn’t be ashamed. We are fighters and survivors, each of these scars has a story of something we’ve overcome in this life, a milestone. That’s something to be proud of, each breath we breathe is a gift and a miracle and we should never ever feel ashamed that we’re still breathing.”

Chelsey

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