



How to be an advocate for childhood cancer by supporting families in need

Laura Lane's interview with Tattoo Tom Mitchell

Episode #15, Hope, Strength and Courage Podcast – Full Transcript

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Thank you for tuning into the Hope Strength Courage Podcast. Love and support for parents whose kids are fighting for their lives! A weekly podcast created to support parents and caregivers of children diagnosed with cancer, where you will find resources collected to help you face each day with Hope, Strength and Courage. From interviews with the top experts in their fields: doctors, psychologists, chaplains and inspiring frontline workers in paediatric oncology as they share their best advice, as well as day to day advice collected from other cancer moms and leaders in personal growth and development . From individuals who understand how hard it can be, I hope you will feel better prepared to cope with the day-to-day challenges of caring for your child. Hi, I am Laura Lane, and I am your host. My own daughter Celeste was diagnosed with cancer at the age of 12. In 2015 I wrote about our experiences in the book “Two Mothers One Prayer: Facing your child’s cancer with Hope Strength and Courage”. Since that time, I have dedicated thousands of hours to share with other parents and caregivers the resources, tools, tips, skills and strategies I learned that helped our family to stay happier, healthier and more hopeful. My goal is to share with you my interviews with experts to support you as you care for a child with cancer.

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Today's episode features my interview with Tattoo Tom Michell, founder and director of Still Brave Childhood Cancer Foundation.

Last week, we spoke with author and cancer survivor Annie Pool about how to turn your child's cancer journey into an adventure.

This week Tattoo Tom shares the work he is doing on a daily basis to support families and advocate for more childhood cancer funding through his creative and fun projects and slightly crazy Ultra Marathon adventures. Tom is an inspiration in how he lives up to his promise to his daughter Shayla to continue to support other cancer families the best way he can.

I hope you will enjoy this interview as much as I did.



I am pleased to formally introduce you to Tom Mitchell also known as Tattoo Tom.

Tom is the founder and director of **Still Brave Childhood Cancer Foundation**, affectionately known as Tattoo Tom by the children and families whom he serves. He's also a nationally recognized activist and advocate for children with cancer and their families

Following the death of his daughter Shayla in 2009 from Hodgkin's Lymphoma, Tom dedicated his entire life to providing non-medical support to children with cancer and their families. He's also committed to raising awareness of the need for more research funding and safer, less toxic treatments for children with cancer.

Dubbing himself and those who work for **Still Brave** as "renegades", Tattoo Tom is always anxious to share what he's learned, grown to understand but refuses to accept. He is very outspoken. His obvious passion, continued activism and his innate need to be a voice for those who do not have one, has led him to being at the forefront of a grassroots movement, being loudly and unapologetically vocal about what matters most - the eradication of childhood cancer.

Please welcome my guest, Tattoo Tom Mitchell.

Tattoo Tom: Thanks for having me.

Laura: So, if you could, give us some background first by us telling a little bit about yourself and your daughter Shayla.

Tattoo Tom: Okay so, in July of 2007 I got a phone call from Shayla. She was living with her mom at the time. And said that she wasn't feeling very well and asked me if I could take her to the doctors, she thought maybe she had a sinus infection or something. So I picked her up and I said sure, we'll grab some dinner afterwards. Well it turns out um, my daughter's sinus infection was anything but; it was actually a huge cancerous tumor that was taking up two-thirds of her chest. It had caused one of her lungs to collapse. So, long story short we were rushed to the hospital and immediately diagnosed with a stage-four Hodgkin's Lymphoma diagnosis. At that time Shayla came to live me with full time, and as a single dad I was faced with a lot of the struggles that a two-parent family might face, but I was faced with them as a single dad as she went through about sixteen months of treatment um, before she finally succumbed her disease and passed away in January of 2009.

My daughter was a teenager, she wasn't a little kid so we had a lot of very candid conversations after we sort of got the, I'm going to give the condensed version, but after we sort of got the hospice situation, we had a lot of very candid conversations about what my life might look like after she passed away, and one of the things that she made me promise is that I would do what I could to help similar families who were in situations that we found ourselves in. There were days where, in spite of the fact that she was fighting for her life, and going to all these chemotherapy and radiation appointments, I didn't have gas money to put in my car to get her there. I didn't have money to buy groceries. It's not because I'm lazy.



I've always owned my own businesses. I've always made a tremendous amount of money, but I just couldn't work. So, we were privy to many of the holes and many of the challenges facing um, a family that has a child that's in treatment for cancer beyond the obvious things. So, one of the things that I did is I promised her that I would do everything I could to help other families, and after a short grieving period after she passed away, that's exactly what I did. So, I've dedicated my life, um, to doing anything I possibly can. We started **Still Brave** a little bit before Shayla passed away, um, and they got real serious about it in about 2011. We got our incorporation, we became an official 501C, and about, I'd say about a year and a half ago, I actually - we got so busy, and so big that I became a full-time employee, well, sort of full time employee with **Still Brave**, its actually my job now.

Laura: Wow that's awesome! So, I have a list of other questions for you. So, tell us about this term "renegades" that you use for yourself and for the people that work for you at **Still Brave**?

Tattoo Tom: Okay, so you can look at me and tell like I'm not your average typical chartered cancer activist or advocate. I'm just not. We don't have a lot of bake sales, that's not how we raise money. There's a song by a band called *Range Against the Machine* and one of the lines = its actually an older song - one of the lines is that "*Renegades are people with their own philosophies. They change the course of history. Everyday people like you and me.*" So, we adopted that phrase. We wanted to be the voice for children with cancer. We wanted to be the regular, everyday people that stepped up and made a change and so we call ourselves "renegades" and we approach everything that way. I don't candy coat anything. If you follow my Facebook or you've seen any of my Ted Talks you'll know that I don't candy coat anything. I'm not a sunshine and rainbows kind of guy. I present to you accurately. I present it to you in real, raw authentic ways. Some people get down with my brand of activism and some people don't and that's okay. It's a numbers game and we do attract a demographic that, um, that is very kind and compassionate that might not be attractive to other, to your average childhood cancer organizations so "renegade" is a very affectionate term. It just means we don't we don't candy coat anything, we're very aggressive in our approach, we're not too interested in following the rules, we don't care who likes us and who doesn't like us outside of the families whom we serve.

Laura: Right. Well, I think that's a powerful term and yes, I know who *Rage Against the Machine* is I remember that.

Tattoo Tom: Oh awesome.

Laura: I had my shaved head days my, industrial, I listened to some of that music years ago.

Tattoo Tom: Great.

Laura: So tell us what services does **Still Brave** provide?



Tattoo Tom: Okay, so again being a single dad, I was privy to a lot of the challenges that a two-parent family would face but I was faced as a single parent. So, what my organization does, some of the many things that we do, and we don't box ourselves in to, um, to necessarily - we keep our doors kind of open. There's really - the only thing that we don't do, and that's why we call it non-medical support, we don't raise money for research. We don't concern ourselves with the research. There are a gazillion organizations out there that are doing that. Personally, I feel as though I would be wasting my money. I think it's going to take millions and millions, and billions of dollars and I think the government needs to step up. If I gave \$470,000 dollars to research that would be a drop in the bucket.

So, my organization, while we certainly support research, I think that that money needs to come from the government, that's a whole other - well, maybe we'll have that conversation too so we don't concern ourselves with research.

What we do is we provide day to day services for families that are in the midst of childhood because there is no cure right now. There is no safe treatment, it's all toxic, it's all horrible, it's a tremendous daunting journey. So, some of the challenges that I was faced with I already spoke briefly about, you know, I didn't have gas to get to some treatments. I didn't have groceries. I couldn't pay rent. So, my organization does that, we provide gas cards. We provide grocery cards. We help with rent. We help with utilities. We do car repairs and improvements. We do home repair and improvements. If you get behind on raking your leaves, we'll send a team of "renegades" out to rake your leaves. Um, in some cases we've assisted with rides to treatment, um, we sadly help to pay for way too many funerals. We'll provide iPads, birthday parties for kids, really, there's nothing that we won't do. If we get a request from a social worker or from a family and it's a genuine need or request, I will charge hell with half a bucket of water in a gasoline suit to meet it.

Laura: Right. That's incredible. That is so desperately needed. That's fabulous. What is the difference between the mission of **Still Brave** and your personal? So, tell us the difference. You're Tattoo Tom. So, what's the difference between **Still Brave** and Tattoo Tom?

Tattoo Tom: Okay. It's very important to note that because while **Still Brave** doesn't concern their selves with research, Tattoo Tom does. So, I am two separate entities. I run and I'm the director of **Still Brave**. You know, that's my full-time job working for them. But we're not concerned with research so what I do for **Still Brave** is separate.

What I do, what Tattoo Tom does, is I go, and I get out there and I talk about the toxic treatments, I talk about the fact that we're treating our kids with thirty, forty, fifty-year-old chemotherapies. These medicines are essentially, we euphemistically call them medicine, essentially, they're poison derived from mustard gas in World War II, and you're likely to find me with a picket sign in front of the National Institutes of Health protesting the National Cancer Institute who only earmarks - in the United States - they only earmark 4% of their billions of dollar budget for childhood cancer research, 4% is not enough. Our children are dying. There's only been three new drugs approved in the past 30 thirty years by the FDA to



treat childhood cancers. I don't understand, I'm not a particularly bright guy, but I don't understand how they think 4% is enough. You know?

I've been to more funerals than birthdays this year. You know, our children are - if they are lucky enough to survive, they're plagued with secondary cancers, they're plagued with chronic health problems, you know, because of the toxic treatments that we're putting in the kids. It's this archaic chess game that goes on and you can tell I'm a little bit passionate about it, this archaic chess game that goes on we put this poison in our kids to try to kill cancer cells. Yes, the chemotherapies do kill cancer cells, but they also kill healthy cells. So, you play this archaic chess game of trying to kill the cancer cells without killing the children at the same time, but the damage done to the healthy cells remains.

So, what I do and what I continue to do, and what I've dedicated my life to outside of **Still Brave** is to make that known, to raise awareness as to what's going on. A lot of people just don't know. They think, in America, well, we live in the greatest country in the world, we've been told that since we were children, "you live in the greatest country in the world". So surely, we must have the most innovative treatments, cutting edge treatments, the best that money can buy. We don't, it's ridiculous. Americans spend twenty times more money annually on potato chips than we do on childhood cancer research. Last year in the United States, Americans spent \$365 million dollars on Halloween costumes for our pets. That's almost twice what the National Cancer Institute spent on childhood cancer research. It's ridiculous. People don't know. People are unaware of it. I'm miffed and dumbfounded and blown away by these - once my daughter died, I went down all these rabbit holes and I found out all these facts, and it's not - what I'm giving you, it's not the crazy raving of a grieving father, these are substantiated truths that I'm telling you.

Laura: I know, I understand.

Tattoo Tom: Its preposterous, you know, its preposterous, that in this country or any other, you know, first world country, that we're not doing everything we can to treat our children. We're discounting them, we're discounting their futures, and, you know, I can speculate why that is, you know - I will speculate. It's about money, and it's about politics and but meanwhile our children are dying as a direct result of it, and it doesn't make any sense. You know, when a ship goes down at sea what do they cry? Save the woman and children first. Well, the ship is sinking, and our children are drowning and we're not doing anything. Our kids aren't dying from cancer because there's nothing that we can do. Our kids are dying from cancer because we aren't doing anything.

Laura: Yep.

Tattoo Tom: And so, I have dedicated my life to making that known. It's a fine line that I skate because **Still Brave** again doesn't concern themselves with that type of aggressive advocacy and activism, but I do. I am very vocal about it. I have done two Ted Talks, you can find them. I gave more statistics and more facts in those Ted Talks. They're very passionate



because I'm very passionate. You know, it's ridiculous to have to say this but I'm going to a funeral on Saturday for a 12-year-old boy and I have, was asked to write the eulogy. It's not the first eulogy that I've had to write for a child. It's not the second or the third or the fourth eulogy I've had to write for a child. And I'm only one person. You know, I'm only one person and I've been to the funerals of more children than I have adults.

Laura: Well, there's something I would like to say to you Tom. I think that that's a testament, that these parents trust you to do these eulogies, that is so incredible that they love you that much and are so appreciative of what you are doing; that's a testament of your heart, that you are willing to do that for these families that you've connected with them, I think that's incredible.

Tattoo Tom: It's a definite honour and I take it very seriously and I'm very honoured and you know, I'm touched by the relationships I have with these families, and I'm glad that in spite of the challenges that I have faced in my own life that I've been able to step up and do this. You know, I consider it a real honour to be asked to deliver these eulogies and to be invited into the homes of these families, and to be trusted, and to be loved by them, and to love them as I would my own children.

So, there is one thing I do like to say, and it's hard to - sometimes I get on a roll about how unfair - but the thing is there's a lot of, I'm thinking of the right way to say this - there's a lot of beauty in what I do, too, even when it's not pretty. You know, there really is. I call it bits of gold amidst the rubble and some of the relationships that I've formed, regardless of the outcomes, have been beautiful and magical. You know, the relationships I have with families, again regardless of the outcome, if a child does well go into remission, the relationship remains. I've established lifelong relationships with these families. If a child passes away, I stay in touch and continue to communicate and have lifelong relationships with them, and the funny part is, you know, a lot of people say that you know, they talk about the help that I provide and the inspire - but you know really, I'm the one that benefits from it. You know, honestly, I think more so than they do.

Laura: Yeah, it is incredible when we give like that, that to be around these incredible children; that they are the inspiring ones, right?

Tattoo Tom: For sure.

Laura: They really are, and they help us. One of the things that I've been saying for the last few years that our children are our teachers. These children who have cancer have so much wisdom, and are so beautiful, and teach us so much, and remind us of what's most important, and it's incredible.

Tattoo Tom: Yep, absolutely I'm a very lucky man.

Laura: So, I'm going to throw out a question at you, that we haven't discussed and that is if you could share three things for parents whose children have cancer, what are the three



pieces of advice that you would give them as they're going through this, as they're dealing with this day to day battle, as they're by their child's side either during treatment or post treatment; what are the things that, you would share? What's the advice you would give them?

Tattoo Tom: So, the number one piece of advice I would give somebody in that situation is to educate yourself. To do your research. It's a scary, you know, it's a scary situation when you have a family of a newly diagnosed child, the last thing you want to do is tell them there's been no new drugs approved in past 30 years. The last thing you want to do is scare them more.

Laura: Right.

Tattoo Tom: You know, it's a tough situation that I find myself in because I don't want to scare a family with a new diagnosis. They're already frightened enough.

So, what I would encourage them though, first and foremost, is I would say to educate yourself because you're going to be your child's biggest advocate throughout the treatment process. You have a say in everything that happens to your child, and you should educate yourself, and you should know the ins and outs and most families with children with cancer become that. They become more knowledgeable or as knowledgeable as doctors and nurses and because we have to, we have to. You know, we have to know what's going in our children's bodies. We have to know the side effects, we have to know what medicines are going to counter those side effects, we have to know what medicines are going to counteract the medicines that are going to counteract the side effects. Yeah, we have to know all those things. You know, so educate yourself, and most parents again will, by default, have to do that. But always remember that you are your child's biggest advocate. You have a say in everything that happens to your child, and you have the right to hold that doctor in your hospital room for an hour and a half until all your questions are answered satisfactory that's satisfactory and if not don't let him out. Turn around and put your back to the door until you're comfortable with every question that's been asked. Now, I have a lot of respect for oncology doctors, and I have a lot of respect for oncology nurses. I think they do one of the hardest jobs in the world, however, as a parent, I do have to hold them accountable, and I do have to help them help me understand everything that's happening to my child through that treatment process and to allow me to have decision making process, not to tell me we have to this we have to do that. I want to know why we have to do this, and I want to know what the other options are. I want to know what's in the best interest of my child, and there were times where I had to get aggressive for lack of a better term, because I am and will always be my child's biggest advocate. And you will too. And that will be the number one most important piece of advice I can give you is educate yourself and be your child's biggest advocate. So that would be number one.

Number two, I would say, I mean this is a funny thing, but when you're going through the treatment process, horrible things are going to happen. They just are. But beautiful things



are going to happen too, you know, so just don't be afraid. Don't ever be afraid because here you are, okay and life is funny, and life will deliver things to us that we don't want and that we're ill-equipped to handle. But how often in life has something been accomplished by somebody who is completely incapable of doing it when they were presented with it, you know what I mean. So don't be afraid. There are a lot of happy endings in my work. There are a lot of kids who go on to do amazing things, and they get they go into remission and they become cancer free and they go on to be nurses and doctors and these amazing child life specialists and they do these amazing things and you know, stay positive and don't be afraid when these horrible things are happening. So that would be the second piece of advice that I would give.

And the third piece of advice I would give would be to the fathers, specifically. And the reason that I would give that is because I am a cancer dad. And that piece of advice would be do not be too proud to ask for help. Do not be too scared to ask for help. Do not be too proud to ask questions. You know, I don't want this to sound sexist, but as a man sometimes we feel like we have to fix everything and we have to keep our families together, and that's our job, and that's our role, and we have to be strong, and we have to be brave. But the reality is the cancer doesn't afford us that luxury anymore, you know, and we have to do what's in the best interest of our children and sometimes that's humbling ourselves and asking for help. Sometimes that's saying I don't have money to pay rent this month, could somebody please help me? Sometimes that's sitting down and crying because you're completely overwhelmed, you know. And sometimes that's reaching out and asking another man for help or advice which is very difficult for, I know it was difficult for a guy like me, so I imagine it's difficult for a lot of men, to do that. But yeah, you're right. Your family will depend on you, and your family does rely on you to hold them together, but you need to understand that you're a human being and you can't fix everything, and you can't do everything and there's no shame in asking for help, and there is help out there. My organization makes it so easy to get help. There's no forms to sign, there's no promises to make to anybody.

Laura: Awesome!

Tattoo Tom: Yeah, you call me, and you need help, I will help you. You could whisper it in my ear. The easiest way for you, like to, we make it easy because I know what it was like. So those would be, if I could write a book of all the things that I would tell a family with a child with cancer, those would be the three most important of things. And that would be advocate for your child, and for men don't be afraid to ask for help, and also you know, it's going to be, just don't be afraid. Don't ever be afraid, you know.

Laura: Well, that's awesome, thank you. Okay, so another question for you. So, tell us about humour. How did you use humour?

Tattoo Tom: Okay, so I use it in a variety of ways. One of the things that makes me maybe attract children to me or makes me attracted to children is I do crack jokes. And I do, I was



just in Seattle for a big race and I met this beautiful little girl who was over from England, to receive her treatment here in the United States, and you know, we would just joke and laugh, and I would put her little girl hat on and we just had fun. And one of the things that I do is I don't talk down to the kids. I don't "oh I'm so sorry you're going, you're such a hero, I'll pray for you, I'll keep you in my thoughts." I think all of that's great, but kids get tired of that crap. Kids are smart and they see that fake pretentious stuff, and they just aren't interested in it, you know. So, I remember one little boy, he was going through a really, really tough time and, people would say things to him like "oh we're praying for you" and I'd say "hey don't poop your pants when you go to your MRI" or whatever, you know. Like we have that kind of relationship. He would send me pictures. I was running an ultra-marathon at the time and he would send me a picture of some guy who was running a marathon and crapped his pants during the marathon and we would have those type of relationships, and I'll crack jokes and I keep it light and I keep it real, and one of the things that I do is I don't treat a child with cancer like a child with cancer; I treat a child with cancer like a child. No, I don't even treat them like a child. I treat them like a human being. I treat them the same way that I would treat you. I speak to them the same way that I would speak to you. I don't talk down to them. I don't say anything that would indicate that I don't respect them as much as I respect anybody. And kids are real good judge of character, and they sense authenticity, and they sense realness, and its really easy to approach children that way and that's one of the things that I do. I do spend, I try to make it fun. I try to make it light. I have a bazillion and one stupid jokes that I give them and they love them, you know, and we have fun. Anyone that knows me will tell you that I'm putty in their hands they can make me do whatever they want, and I'll do it.

Laura: Well, that's totally awesome thank you so much Tom, that's just that's just incredible. So, my very last thing I need to of course ask is what website can we send our audience to so they can learn more about you, and they can learn about **Still Brave?** Where can we go?

Tattoo Tom: Okay. So, our website is stillbrave.org - www.stillbrave.org. So, you can find out all the information about my daughter, my daughter's story; you can see my Ted Talks; you can see the different events and fundraisers that we have; you can get all the information, really everything that you want is there. I would encourage you, too, though if you would like to follow me and my organization on a day-to-day basis, find us on social media, Facebook; I post daily. I post with the permission of the parents and the families - I post pictures of kids who we call them **Still Brave families** and the different things that we do; the activities that we do; I'm a huge - like I say, I'm a huge activist so there are two separate pages - there's the **Tattoo Tom** page and the **Still Brave** page. My personal page I post a lot of activist stuff. I post a lot of advocate stuff, not so much on the **Still Brave** page because again that's not our mission but you could follow me on a day-to-day basis and see me in the clinics, and see me in the hospitals, and see first hand the work that we're doing where your charity dollars are going and the events that we put on. We put on a lot of events that are just fun for kids. We have Carnival of Kindness which is this big event where hundreds of kids come out, and we



don't charge anything, and free ice cream, free cotton candy, music, everything's free. And then one day we might - we have a rock concert that we put on once a year called Rockin' Renegades and we, you know, you can follow all of that stuff and we do all kinds of cool stuff. There's a big event in Washington DC in a couple of weeks called Cure Fest and a bunch of organizations come from around the country and **Still Brave** is one of the biggest supporters of that event and we'll be setting up the kids tent there, at the welcome event, and you can follow all that stuff on my Facebook as well.

Laura: Oh, that's awesome that sounds terrific. Thank you so much, Tom, this has been incredible. I've just really enjoyed getting to know more about you, and your humor is wonderful and your passion. I just think that that's incredible what you're doing and thank you, thank you so much. Having been there myself and knowing how hard it is, I know the service that you are providing is just incredible.

Tattoo Tom: Well, thank you so much. Thanks for having me I appreciate it.

Laura: Take Care.

Tattoo Tom: Alright

What impressed me most about Tattoo Tom was his ability to recognize so many needs of cancer families and in the words of Mr. Bigweld from Robots "See a Need, Fill a Need", he stepped up to the plate to do exactly that. I think what he is doing with his organization Still Brave is amazing.

If you currently have a need you are struggling to have met, please, please, reach out and ask for help. There are people and organizations that want to be there for you. People are amazing if only you will let them. The reason I do what I do and Tom does what he does is because so many people helped us when we needed it. Let us do the same for you. This is the legacy of our own amazing, caring children.

To learn more about Tattoo Tom and the Still Brave Organization please visit his website at <https://www.stillbrave.org/>

Please join me next week for part one of my interview with Dr Mark Setton as we discuss the Pursuit of Happiness Organization and 7 Habits of Happy People and how caring for others can make a difference in our own happiness.

Before we end our show today, we have one last segment. Over the last few years, I have asked other cancer moms what advice they wish they had known when their child was first diagnosed. I have compiled that information and will be sharing their advice each week. You can download the top 101 pieces of advice that I put together as a mini E-book at www.twomothersoneprayer.com

Today's advice comes from Karen.



Karen writes: I would have liked to know how the treatment program actually works. For all the side effects we are told about, I was still missing the big picture while instead being told about the pixels in the picture. When Ella was admitted with sepsis, I had not been prepared for the severity of the illness. One nurse told me “When you went home we knew she’d be coming back soon.” I was never told that any sign of illness after that round of chemo would result in an ICU stay – I learned that as we were being admitted to the ICU.

Thank you Karen, for sharing that. It is a reality that we need to face, that this will be an uphill journey. That our children will have days when they are very, very sick. It will require many extra trips to the hospital that you won’t anticipate. But the staff are skilled and prepared. They are there to assist and do everything in their power to help your child. I would highly recommend listening to my interviews with Dr Geoff McCowage, Paediatric Oncologist. He addresses this very issue. If you haven’t listened to it already, I recommend both episodes as well as seeking out his podcast series “Understanding Childhood Cancer With Dr Geoff”

If you have advice you have learned along the way that you wish someone had told you weeks, months or years earlier, I invite you to fill out the contact form on our website www.twomothersoneprayer.com and I will be sharing your advice with our listeners on future shows.

[Music begins lightly in the back ground]

Thank you for taking time out of your busy schedule today to listen to the Hope, Strength & Courage podcast. I look forward to sharing more experts and advice with you again next Wednesday. Please remember to take a minute to subscribe to the show. Thanks also need to go out to our Hope, Strength & Courage production team which consists of my wonderful assistant Tracey Ogilvie-McDonald, Andrew Braun at Braun Audio and Audio Geek, music by Fiz Anthony, social media support by Marife Constantino, and graphic design by Amy Hosmer. To learn more about myself, Laura Lane, and to order my book, please visit ww.lauralane.ca.