

## VCS Alumni Podcast Episode 4 – Steve Hilfiker VCS '84 - Transcript

### Speaker 1 (Tom Turner)

Welcome to the 4th installment of the VCS Alumni Podcast. This is the podcast where we catch up with alumni and provide an update of where are they now and what are they doing. I'm your host, Tom Turner, and I was a 1990 graduate, in Victor. Today's amazing guest is Steve Hilfiker, from the class of 1984. Steve is a film producer, a former CEO with 32 years' experience in business. He was a successful environmental and cardiac advocate with extensive relationships in the Florida legislature. During his environmental career, he was the founder and President of Environmental Risk Management Incorporated and currently serves on the board of Directors of Florida Ground Water Association (FGWA). He has served in similar environmental association roles since 1991. An extended battle with a misdiagnosed cardiac sarcoidosis resulted in a successful heart transplant on August 3, 2020. As a man of faith with a youthful heart and a clean bill of health, Steve is using his skills to raise awareness for organ donation and sarcoidosis, including proposed research, appropriations, and funding grants for early detection of cardiomyopathy. Producer credits included "StoneHeart: An Undying Gift" and "Warriors: The Bernie Mac disease". Current film projects include a true story feature film and a docuseries about organ donation, Sarcoidosis and cardiomyopathy. His awards include FGWA 2021 Man of the Year. 2022 Leader of Life from the American Heart Association. 2023 Dorothy Bland Sarcoidosis Warrior of the Year', The Bernie Mac Foundation. 2023 – Official Selection for the '2024 LifeLink Faces of Transplantation Calendar, a frequent speaker and writer, Steve was the founder of Hilfiker Life Missions LLC, a film production and media company. Sarcoidosis, Transplant, Organ Procurement & Cardiomyopathy Foundation Inc., a 501c4, Foundation for Organ Donation and Sarcoidosis Awareness, Inc. (FODASA), a Florida non-profit organization (501c3 status pending), and MCG USA, LLC, a medical equipment sales and consulting company. And having said all that, Steve, welcome to our VCS podcast. Thank you for offering to share more of your incredible life journey with us.

### Speaker 2 (Steve Hilfiker)

Thank you for having me. It's a pleasure to be here. Sounds like I need to shorten that bio a little bit.

### Speaker 1

The copy of War and Peace there, anyway. Let's kick things off by going back to your early years. Can you share some background on your time at VCS with us?

### Speaker 2

Sure. Yeah, I loved my years in Victor. It was such a wonderful place to grow up, wasn't it? I mean, the Fireman's Carnival and Riccio's, and skate place. You know the old bowling alley before the skate place. It was just great. I moved to Victor, when I was 6. So basically, got to spend all the years from 2nd grade, right on through graduation in 1984 and. Just, you know, loved the school, the campus, everything was on one campus. I think that was unique to the region where Victor had all of its schools on one campus and it. And I think that really helped foster a lot of community and friendships. By all the baseball fields, everything being in the same place. Yeah, I loved it.

### Speaker 1

Yeah, It's like a city now. You wouldn't even recognize it.

Speaker 2

I know I've been back quite a bit and we lived there in the glory years, so we're just, I often think of the old downtown. You know cobblestone building there on 96 and it burned in 1973 and remember. How unfortunate that was for the Village of Victor because it was just such a beautiful landmark historical building.

Speaker 1

Yeah. Yeah, it was.

Speaker 2

All those years, 70s and 80s, not a bad time in life.

Speaker 1

No, no, those were the best times of our lives and short lived, unfortunately.

Speaker 2

You know what I tell a lot of people about growing up in a small town like Victor. You know, nobody had to lock their doors. People did, I'm sure, but that was trust. It was friendship. It was, you know. You knew, everybody knew everybody, and everybody got along, you know, it wasn't a lot of drama. It was just a beautiful time.

Speaker 1

It was. It truly was.

Speaker 2

I have very fond memories. We had a lot of fun too, you know, Powder Mill Park and skiing at Bristol Mountain and parties in the basement and, you know, just pool table and you know bonfire parties. And we, we had a lot of fun back in the day.

Speaker 1

Yeah. Good times. Talk to me a little bit about the University of Florida. What made you choose that school for your master's degree in environmental studies?

Speaker 2

My parents moved to Naples FL after I graduated from high school there in Victor. I went to Geneseo, had a blast at Geneseo was president of Phi Sig. And then as a geography, environmental major, the University of Florida had a great program and I wasn't sure what I wanted to do yet, so I figured I'd keep going to school because University of Florida had a reputation for being absolute fun, great football team. And so, I figured I'd go get a master's degree and figure it out. Well, that's the story.

Speaker 1

OK.

Speaker 2

It was fun. Emmett Smith was there at the time, and the football games were great. So, college and grad school experiences were, you know, were fantastic as well along similar fun in high school, fun in college, fun in grad school. And then after grad school I ended up here in Southwest Florida, the Naples, Fort Myers area.

Speaker 1

I'm looking out the window right now and I'm seeing the snowfall and the icicles on the trees, and I almost feel stupid asking this question, but what made you stay in Florida for your environmental engineering career?

Speaker 2

Well, I wanted to go back and hang out with all my friends in New York. After UF, my plan was to go back. Get a job and I did. After defending my thesis went back. It was October of 1990, but the economy in Rochester, Victor was no good. I got a job waiting tables. But that's the best I could get. And I spent Christmas with my parents in 1990, answered an environmental job in the newspaper, and started my environmental career on January 5th, 1991.

Speaker 1

Oh wow.

Speaker 2

Immediately was on the Board of Directors, gravitated toward leadership positions. A lot of those skills I learned in the fraternity believe it or not. And just continue to lead environmental associations and always been kind of entrepreneurial. So, I started an environmental firm and a construction trailer in my backyard in 1999. And build that up to substantial revenues, 22 employees. And very, very proud of that company, Environmental Risk Management based in Fort Myers going, we're we'll be starting our 25th year coming up in 2024.

Speaker 1

Incredible, congratulations.

Speaker 2

Well, thank you. You know, I'm still a shareholder. Maintain a role, primarily industry leadership and. Still on the board of Florida Groundwater Association, what we do is we keep the drinking water clean, we do groundwater assessment and remediation services to protect Florida's groundwater.

Speaker 1

Noble effort. And badly needed, unfortunately.

Speaker 2

Yeah, with the population of Florida, you know, we get it. Uh, we look at other things as well but the in the environment in Florida, our main priority is. There's no more important resource than groundwater, so that's our priority.

Speaker 1

No, I agree.

Speaker 2

We're looking at sea level rise. We're looking at overpopulation. Deforestation doesn't just happen in Brazil. You know, so redevelopment is critical in Florida trying to redevelop infrastructure. Yeah. So, I've been working on those things in the Florida legislature with friends in the Senate and house.

Speaker 1

What's the political environment like with that? Is it tough too?

Speaker 2

It's actually been very favorable for Environmental Protection since Governor De Santis came in. He put forth many initiatives for Environmental Protection. My father hired Senate President Kathleen Passidomo in the 80s. So, I got to know Senator Passidomo, as she was coming up. Well, I had known her for 40 years, but once she got into the house, we started to meet twice a year, once in Tallahassee, and once in Naples. And she and I have a very good relationship and we've gotten quite a few very important initiatives passed in Florida for Environmental Protection and redevelopment.

Speaker 1

Fantastic.

Speaker 2

And that that taught me a lot those, you know, 32 years as a CEO. And you know, a couple at least 20 years walking the halls of the Florida legislature. Really the same job description as a film producer. Can you get it done? Can you get the appointment? Can you do it on, you know, on time and under budget? All the business and lobbying skills. Led to this, you know, new life after heart transplant.

Speaker 1

Tell me a little bit more. I know we talked about your time in Victor. Growing up, but talk to me a little bit more about, you've got a beautiful family there. I watched a couple of videos with your kids and your wife. UM. If you can, compare your kid's life in Florida, in the in the Florida Gulf versus growing up here in little Victor in upstate New York.

Speaker 2

Well, my kids are my pride and joy. I've raised them solo since 2008. My ex-wife, she moved up to South Carolina in 2008, so I've been raising them very, very proud of my children and investing 15 years of my life to make sure that they were good and balancing, you know, managing, raising parenting four children with running the environmental firm. That was you know, we were together, me and the kids frequently,

we'd do a lot of vacations. Go boating a lot, in Florida, of course. It's the amusement parks city annual passes, Busch Gardens, Universal, Disney. You know, we'd rotate. I coached all their teams. We were a very close family and can't wait to see them later tonight. For me, growing up in Victor, older sister, Margie, shout out to Margie and younger brother Doug. And my parents. It was just a wonderful place and time to grow up. I was running around the woods, and you know, off Hunters Run. We had a wonderful neighborhood. Lots of friends off Dryer Rd. there. And you know, in the younger years, it was playing kickball and swinging on vines and building tree forts and just having a blast running through the woods. And you know, school, Little League, 3 sports. It was, you know, soccer or football or basketball. And then once we started skiing, it was Bristol Mountain, wonderful place to grow up significantly different lifestyle for my children. I mean, growing up in the rolling hills and the beautiful glacial terrain of Western New York and the Finger Lakes. And Canandaigua Lake and skiing at Bristol and running around the woods. Here in Florida, you grow up, it's about beaches and theme parks and you know to go with the five of us, with four children to go anywhere on vacation, it was too expensive to fly and to get out of Florida from South Florida, it's at least a six-hour drive. So, our options were this, the Southeast Georgia Mountains. So that turned out to be our annual trip. Every year we go up to the mountains northeast of Atlanta and have some wonderful memories doing that.

Speaker 1

I want to know a little bit more, we'll get into your health recovery, part of your story. Talk to me a little bit about your early symptoms. Kind of the process for a diagnosis and your decision to move forward with heart transplant, speak to me about that.

Speaker 2

Well, that was an easy decision. I wanted to live.

Speaker 1

Yeah. Yeah, yeah. You wanted to live. There you go.

Speaker 2

Life is good. Don't take it for granted. Basically, I think that, you know, we've interviewed 50 participants on 4 continents, and I'm sure we'll get to that. But every one of the sarcoidosis warriors that we've interviewed talks about stress being an exacerbator to this disease. Sarcoidosis. First thing is pronunciation, making sure everybody knows how to say it's sarcoidosis.

Speaker 1

Yeah, I. The tongue twister.

Speaker 2

It's something that everybody needs to be aware of because people are dying from this disease and many people don't even know they have it. In statistics, we've seen that it's found more times. Cardiac sarcoidosis is found more times than not in autopsies. It's an immune system disorder that can affect your eyes and your skin, your lungs, your heart. As an environmental professional, I can understand the toxicology. If you get it in your lungs and that can move to your heart, but if you get in your lungs, it's inhalation eyes and skin absorption and ingestion. If you get it in your internal organs, you basically are

exposed to something, something that weakens your immune system. There's clearly an environmental trigger. It's also known to be a genetic predisposition, so in 2014, I had 104° fever, but I was fine the next day other than a dry, wispy cough. I had seasonal allergies. Sinus infections every February, it seemed, and since this occurred in February, I believe this was an allergy related, weakening of my immune system and sarcoidosis is an opportunistic disease. Once your immune system is down somehow, what they're called granulomas form. In whatever organ is exposed and, in my case, I believe it was inhalation in February in Florida we have green tree pollen from the pine trees and that dust that you can dust the cars with it. I mean you got to dust off your car. So, I believe that exposure in my lungs of excessive pollen weakened by immune system and started the disease. And it can migrate, it's a strange disease. It can move from organ to organ and eventually took a few years but moved over into my heart. I started having cardiac symptoms in 2017. But that was the onset and the exposure.

Speaker 1

It sounds like from you know, reading your bio here. Your career seems to have shifted from that, that whole health experience with sarcoidosis and almost losing your life. Talk to us a little bit about how you've used that experience and your business and engineering skills and those experience have also led you to help others with the with your foundation and. Your film and media company. Talk to us a little bit about that, if you would.

Speaker 2

Yeah, that's, that's where things get exciting and interesting. So, in 2017 I have to share a little bit of faith here. I, on the day they told me that I needed a pacemaker and I it was the first I realized I had a major heart condition. I did a Bible study in the verse was I will give you a new heart. I'll put a new spirit in you. I'll remove your heart of stone. And I'll give you a heart of flesh. That's a scripture from the Old Testament. And it was incredibly powerful to me because that's exactly what happened. Cardiac sarcoidosis turns your heart to stone. And I'm not sure I'd be alive today without my faith. And it was just I. I never had any fear. I knew I'd survive. I knew that I would pull through this to be able to share this story. So as the heart failure progressed from 2017 with a pacemaker and just got worse and worse and it was being misdiagnosed, they couldn't tell me what caused it. I had stress tests and other diagnostics that should have pointed to sarcoidosis. But it's, you know, in fairness to the doctors, it's difficult to diagnose this disease. Which is the main one of the main parts of our mission is to spread awareness about it, so doctors, don't miss it anymore. But being misdiagnosed for five years, you know, had they given me the right test in 2017, I would have been fine with the pacemaker and not have required a heart transplant. That, as things unfolded and the heart failure progressed, I was getting sicker and sicker every day. I couldn't walk a flight of stairs without having an incident. And my children are watching me fade. I'm on a slippery slope. And then COVID comes along. Finally gave me a diagnosis. You know, I had to come up to New York, UR, go URM, Strong Memorial Hospital. Those were my heroes. They gave me the diagnosis. And the amazing thing was I had to go up quarterly for treatment. And then COVID hit. So how do I get up there like the plane stopped? And travel stopped and I was at my worst at about March of 2020 and desperate for this April of 2020 appointment. And the planes were down, so we rescheduled it for June. Had I missed that June 2020 appointment, I'd be dead right now. And flights were still down, so we had to drive to Florida. So, I took my two of my two boys. I've got two boys, 2 girls, Olivia, Ben, Audrey and Matthew. So, Ben and Matthew came with me, they're now 27 through 20. Anyway, we drove, and they basically told me I was an end-of-life stage D. Heart failure, and I only had a few weeks to

live if I didn't get a heart transplant. I came back from that, told my kids not only am I going to survive this, but I'm going to ski again. They referred me to Tampa General Hospital where I had all the transplant testing done in 11 days. Every test in the world is done and at age 54 at the time, otherwise healthy, the disease contained only in my heart. The rest of the tests were perfect. And being a single father of four kids, I scored pretty high and all the criteria necessary to get listed. So, I go back home and a couple of days later called the Doctor up said I don't feel well. He's like, get up here right away and my heart failed on the way to the hospital. My sister got me to the hospital in time, and as my hearts failing the medicine, they gave me to revive the blood pressure didn't work. So, they put me on a balloon pump. My hearts essentially dead in my body, my body, my blood flow was maintained through a balloon pump. I was and then I got 7 heart offers, in three days, which I consider another miracle. I mean, people wait two years, I got 7 in three days. How's that happen? The answer is life support. That's one answer. To me, it's a literal death and resurrection story because I was on life support for three days. So that was my tomb and resurrected through a heart transplant. But that was August 2020, middle of COVID and I was essentially dead and not up for a surgery like that, so I had sepsis, Pneumonia, Cardiogenic shock. Stuff you don't survive, and they decided to put me into an induced coma. And near-death experiences, which were fascinating, the sensation was my brain was spinning backwards in my head. It was very transitional, like a spiraling, like a transition of energy into the next World. And in the ICU, the lights are always on and you know, I heard young, stressed voices that I perceived to be my children. Or people at church or staff or friends. Anyway, I'm in this out of body kind of experience talking to God saying, you know, I believe I was crying saying why in the world is everybody so mad at me and cause what I was perceiving was the stress of the ICU doctors and my children, so I converted that stress in my mind to you know what's going on? Like what have I done? And. And I remember saying, I just, I just. I just want a puppy and I didn't want a dog. I didn't. It was the cry of a 10-year-old boy wanting to go back and take care of his children.

Speaker 1

Right. It's interesting how that manifests itself. Into that your regression so to speak.

Speaker 2

Yeah, it was very like it was. I was. It was a near death experience. I didn't physically die. I didn't cross over. I didn't see lights or rainbows or what people report, but I did sense. You know how kids will press their face up against the glass at the zoo to see the shark or the tiger or whatever. That's and that's what I perceived, except for it was on the other side. Like I couldn't cross over the barrier. I didn't cross into heaven, but I did feel the presence of energy and spirits. Souls. I don't know if it was my best friend. You know my mom. People that have gone before the donor. You know who knows who it was? But. I did have that experience that was very real, and you know, skeptics will say it was the drugs. I completely disagree because of the consistency, and the, you know the clarity and the consistency of the experience. Fascinating. And then the recovery began after that.

Speaker 1

Wow, there's just no words to explain something like that. I've had similar situations. During my 18 operations that I've had. It's almost like a dream like state where you're seeing dead relatives and I think I found myself in an elementary classroom. My old elementary classroom for some whatever reason as an adult. Very strange. Very, very strange.

Speaker 2

Yeah, it was life changing for sure. And with that experience, you know, when you essentially die and without the new heart, I'd be dead. You get a perspective on life that you can't get any other way. I mean, you just want to give back, you want to. You can't shut me up because I just want to tell everybody I want to share everything, so nobody has to go through this experience. It's so life changing, and you know, some people refer to it as a calling. I think it's more than a calling. It's a duty. Because I have knowledge that saves lives, I've been through a lifesaving miraculous experience that can help others facing the same thing. One of the greatest joys I have is when people will call me up and say, hey, my buddies about to have a heart transplant, he's scared to death. Can you talk to him? And we got on the phone. And you know he's beginning of the call, scared to death at the end of the call, excited. Can't wait for the heart transplant because he knows he's going to get a healthy heart and a new chance to feel good again. And it's just a matter of, I mean the miracles of modern medicine, I mean. I don't want to go too far with this statement, but it's just another surgery. Obviously, it's a complicated surgery. Obviously, it's a risky surgery. Obviously, it's not just another surgery, but if you look at it that way. It is a surgery. There's anesthesia. You go under, you get pain medicine at the end, and you get rehab. So, focus it on, I'm going to have surgery. I'm going to have pain medicine at the end. I'm going to go through rehabilitation and then I'm going to be fine. And if you take that approach, which is what I did once they got me up on the walker, you get right into cardiac rehab, and you're hooked up to EKG's and on walkers and treadmills and ellipticals and rowing machine and I gave it my all. They pushed me and I just nailed it in cardiac rehab and 90 days after hospital discharge, I climbed Sharp Top Mountain in Jasper, GA and that was my moment of victory. That was my moment of recovery. That's when I knew.

Speaker 1

I guess, I guess it was.

Speaker 2

To myself. That I had conquered this disease. And that was powerful and inspiring, and another wonderful testimony of faith. So, we made a movie about it. My nephew, Nicholas Markart, is a film director, went to Florida State and went out to LA after graduation. And he we just made a quick film about we called it Stone Heart about my heart transplant recovery. And it made it the Cannes Film Festival. And we said, holy smokes, we're onto something. So, we decided to interview 50 people on 4 continents, including Rhonda McCullough, Bernie Mac's widow. Bernie Mac died from the from sarcoidosis. He had pulmonary sarcoidosis. And that film made it back to Cannes Film Festival. And we've been tearing it up on the Film Festival circuit and raising awareness throughout the world through these films and our foundation. It's called the Foundation for Organ Donation and Sarcoidosis Awareness. And it has been fun and meaningful to be able to share this story to be able to, you know, film festivals are a blast. And but the meaningful part is to be able to take somebody, talk to somebody, take them under your wing and coach them through. It's a very challenging disease. That causes a lot of pain, a lot of fatigue, a lot of aches and pains, and if you get it in your lungs, you get shortness of breath and all the pulmonary symptoms. If you get it in the heart leads to heart failure. Skin, eyes, the lesions and the rashes and the red spots and the soreness. It's just not something you wanna get.

Speaker 1

Incredible. Could people access that film? Through maybe, Netflix.

Speaker 2

We're trying to, well right now, it's still on the Film Festival circuit. We've got one more Film Festival in January here in Florida in Orlando. It's called CENFLO. Shout out to CENFLO. We've won, Nick won best Director of short documentary. We've won numerous awards at several film festivals. I'm the producer. He's the director. I've self-funded all of this and that unfortunately is unsustainable. So, we're looking to do fundraisers and the foundation will be having a membership drive. We'll be looking for members to form committees, and we'll be seeking sponsors for our events. Event sponsorships and contributions will help us to continue to make life-saving films and put the rest of our fifty interviews together. I have to tell you a little story to demonstrate the power of what we're doing. One of the 50 interviews was Lindsey, who lives in Erie, PA Lindsey Allgeier, and she had a heart transplant at age 17. And she was absolutely determined to be a mom. A woman of strong faith, supported by her wonderful husband Adam. They decided they were going to have a baby, the doctor said no, can't do that. The medicine will cause miscarriages, you know, could cause birth defect, could damage the child. But also, it's too hard on your heart. You just can't do it. And she fought and they fought. And they've two years. And finally, the doctors gave in. And understanding the risks they signed, the forms and everything. The key point here is she was told her whole life. That restrictive cardiomyopathy was not genetic, that her disease was not genetic. So, we got to interview her and her two beautiful baby boys, Isaiah and Jonah. And Jonah, in August of 2022 is telling us how strong he is, how he can lift the house. He's five years old. He's just a cool little kid.

Speaker 1

Neat.

Speaker 2

And in November, she calls us and crying, and she says Jonah's got it. And This is why we do what we do, because we need to raise awareness on these. Her disease clearly was genetic. We interviewed him again in December and he's saying things like, I want to help other little boys and girls, you know, go through what I'm going to have to go through. And as that as my mommy went through a heart transplant. So, we've interviewed him and then about a month ago, 3 weeks ago, somewhere in there, he basically had cardiac arrest in his parents' bedroom at 4:00 in the morning. And wonderful parents, they had defibrillator, they had CPR training. After three minutes of thinking, he was gone. They brought him back and he was airlifted to Cleveland Clinic, where he is right now, Cleveland. OH, Cleveland Clinic. He's not leaving until he gets a heart transplant. The family needs financial support, you know, and that's on my Facebook page. We just posted a few videos about Jonah and his journey, and you can see all that right now on Facebook posted today, December 19. And yesterday as well.

Speaker 1

Right.

Speaker 2

But that's why we do it we do. We try to help cardiomyopathy. We want early detection for cardiomyopathy. I'm working with Senate President Kathleen Passidomo on trying to get advanced

screening and imaging approved and more mainstream and more utilized because the advancements in imaging and screening technologies are incredible and I hope together with the foundation, we have a 501C4 for legislative and political work, research and grants. And the 501C3 is, we expect that 501C3 designation any day we've submitted all the proper forms with the IRS, the board has formed. That's the foundation for organ donation and sarcoidosis awareness. So that's near and dear to my heart, quite literally, to be able to raise awareness for sarcoidosis. Reduce the number of people dying in need of waiting for an organ and reduce the number of people dying of cardiomyopathy. I think we can save hundreds of thousands of lives with research and advancements in imaging and screening technologies that are already out there. They just have to be implemented.

Speaker 1

Sure, sure. I truly believe that there is a cure. I was born with, as you know, spina bifida. And I truly believe that there is either a cure or the biggest thing now is this imaginary cliff that they're talking about. 20-30 years ago, individuals with spina bifida weren't living into their adult lives. They unfortunately had a short lifespan due to lack of medical advancements and things of that nature, but now there's this huge undertaking within the spina bifida community to increase research and medical advancements to make sure that individuals with spinal bifida are living into their golden years. And I'm going to be 54 this year, so 60s insight and actually looking forward to getting old.

Speaker 2

So, trust me, hang in there. Never give up. That's the battle cry.

Speaker 1

No, never. Never ever, ever.

Speaker 2

We're working on those types of things. You know that our healthcare system unfortunately is, due to economics, I think is primarily reactive and not proactive. And then if with more screening and imaging and proactive medicine, I think we'll make some advancements and there's a lot of organizations out there banging the same drum and calling for the same type of you know, improvements. I have a, my case study is a classic case where chronic disease, overlooked because one of our cardiologists says to a hammer everything looks like a nail. Meaning to a cardiologist, if we report with chest pain, they're going to automatically, well, they're going to generally think it's most likely due to your arteries and cholesterol, and unfortunately, the more chronic, less obvious conditions like diseases of the heart muscle, cardiomyopathy, myocarditis, things like that, like I had cardiac sarcoidosis, is a form of cardiomyopathy. The disease of the heart muscle. It's chronic, slowly developing. I'm drafting a book about my case study called Chronic Injustice. And it's gonna be mostly about my case study. But, you know, I hope to be able to make speeches and sell that book and to raise awareness again on the difficulties of reactive instead of proactive medicine. And how it affected me personally. We've got another book, more of a drama, more of an autobiography, but it won't be boring. It'll be pretty cool or pretty funny and relatable to everybody who can relate to relationship conflicts and all in the past. By the way, but relationship drama, business conflict and health issues, it's called More Than One Heart Could Handle. And once we get that book.

Speaker 1

Another title.

Speaker 2

We're going to convert that hopefully to a narrative drama, to a film production studio and hopefully get that in the theaters. But the goal, you know, this isn't about me. This isn't about money. This is about raising awareness. This is about saving lives. It's about, you know, for people that we'll never get the disease and aren't concerned about it. They can still have the takeaway message that, hey, we all have something. We all have sarcoidosis of some kind. We all have something we gotta get through and the more you can face that with acceptance and move on past it, the better life's going to be for you. You know, that's the love, the Serenity prayer, you know, God grant me the serenity to accept the things I cannot change, the courage to change the things that I can, and the wisdom to know the difference. I mean that, that prayer just sums it all up.

Speaker 1

Certainly does. It's one of my favorites.

Speaker 2

Yeah, we all have to come to acceptance over the circumstances in our life that we can't change. And but you got to have courage in this world to live in this society.

Speaker 1

Tell me about it.

Speaker 2

And wisdom, wisdom doesn't hurt. Understanding is so important. You know, loving one another, showing some understanding and forgiveness. Important things in this world. You know I like to say peace, faith, hope, love and joys. You know, we all want peace, faith, hope, love and joy. And if you look at it. Hope and faith are actions and investments. You have to have hope. You have to invest hope. You have to have faith. The results, the return on those investments are peace and joy and to the extent that you're hopeful, truly. And with faith. Trusting that everything's going to be well, and you know, faith is the opposite of fear. So, if you're living in faith, you're not afraid. If you're living in hope and faith, you're not struggling from fear and worry and anxieties of the world. And the results of those investments are peace and joy. You know the way to find peace is to live without fear. How do you do that? Well, you've got to invest a little bit of hope and faith and confidence and courage and have some acceptance. Have some understanding, some wisdom. And you know this, nobody said this was going to be easy. Let's face it. Accept it. Forgive. Move on, love one another. It's not so hard. Let's do this. Life is good.

Speaker 1

Yeah, I agree. I agree.

Speaker 2

That's where I'll, that's the foundation, that's the message of hope. That's what the films all try to center around. Nick Markart, the director, my nephew Margie's son, fantastic film director. Very, very creative. You will see his movies in theaters someday. He's only 27 and we've won numerous awards with our documentaries and hope to have an episodic documentary series streaming on one of these streaming services, but it's going to take a couple of years, you know. We've got to raise the funds to finish the projects. And hopefully with the books turning into feature films all on this same line of hope and you know, health and you know, they're very relatable stories. That we're telling through our documentaries and through our films.

Speaker 1

And I should mention to everybody that you and I put our collective efforts together to create a Go Fund Me campaign. If people wanted to check it out and donate to it. UM. It's the foundation for Sarcoidosis and heart transplant or organ transplant research.

Speaker 2

Yeah, it's the foundation for organ donation and sarcoidosis awareness. We're actually trying to.

Speaker 1

Right there you go.

Speaker 2

Come up with a summarized name, foundation for organ donation and sarcoidosis awareness. That acronym is FODASA [fodasa.org](http://fodasa.org), is a way that people can donate, and the Go Fund Me. I'm not sure where that is. Is that on Facebook?

Speaker 1

I've plastered it all over my Facebook page.

Speaker 2

What I'm so grateful for you for doing that, Tom, that you know, I've self-funded this about as far as I can take it. I can go a little farther. We've got films to enter into 2024 film festivals, and we're not going to stop. It's just going to; I just don't want it to slow down too much. So, to maintain the momentum and to maintain if you just scroll through Facebook, you'll see how much we've accomplished in the last two 2 1/2 years. It's saving lives. It's truly a great cause and to continue the momentum we do need that support. If people are unable to support significantly financially, we are seeking membership support, volunteer support, committee involvement. There's going to be some very fun events. We had the Victor night of hope at Eastview Mall back in August. The Rochester night of Hope was at the Little Theater. We're going to upgrade those events with music and just these are all plans and visions for fun fundraisers and pull our friends together and raise awareness and have a fun and meaningful event, auctions, dinners, concerts. That's my favorite. I can't wait. I'd love to do something like a Live Aid for cardiac care.

Speaker 1

Wouldn't that be great?

Speaker 2

Well, or something like that. But yeah, the Skys the limit. Let's have fun saving lives.

Speaker 1

Speaking of concerts, I know a lot of us saw the article and video about your recent experience at an Elton John concert.

Speaker 2

Oh yeah. I can't believe we haven't talked about that yet. Gratitude to my donor, his name is Daniel, and any Elton John fan will know the lyrics of the song Daniel. Daniel, my brother, you know, do you still feel the pain? Lyrics of the song are just like the life of the man. And so, I met Daniel's sister and actually the film we're making right now is called Daniel, My Brother. I asked Vanessa, Daniel's sister in our first meeting, if she wanted to go to Elton John shows with me. So, she did, and I had a sign saying heart transplant from Daniel. She held a sign saying Daniel is my brother. And we brought stuff to scope in. We would make friends with the security guards, and they would let us ahead of the front row. During the song, someone saved my life tonight, she would listen to her brother's heart.

Speaker 1

Wow, what an incredible story.

Speaker 2

Yeah. So, the newscasts got a hold of that. We've, I don't know, it's just it's a meaningful story. Lost count of the number of broadcasts, press releases, podcasts, articles. It's just powerful, inspirational. I like the song I'm still standing. You know, if I can get Elton John to play at a Live Aid for cardiac. Air type event. I just asked him to play Daniel and Someone Saved My Life Tonight and I'm Still Standing. Just three songs. That's it. Would you do that? That'd be wonderful. And be powerful.

Speaker 1

Well, maybe that's something you and I can work on.

Speaker 2

Yep. And if anybody out there knows how to get through to the guy who knows the guy, who knows the guy to get a hold of Elton John and I would like to talk to them. Because I think this is a mission he would embrace. He's a man of causes.

Speaker 1

Oh, absolutely.

Speaker 2

And it's the type of thing that I think he would do in his retirement and, it's a beautiful story, the song Daniel is very powerful. Ten days after I learned I was going to have to have a heart transplant, I saw Elton John in concert. Of course, knowing nothing about the donor. And I recorded the song Daniel and the video that plays behind the drummer and concert is a young man laying flat on a masseuse bed, no

shirt. And he ages in the video to an older man, and in the video kind of looks like me and the lyrics of the song say, "Oh God, it looks like Daniel." But anyway, that's a side note. The main point is the video metaphorically is Daniel, The transplant. And for us that moment of aging in the video is extremely powerful. You know you can Google it. Look, just Google Daniel live. YouTube will show you on your phone the Daniel Song and concert and you can see exactly what I'm talking about two minutes, two to two to three minutes into the song, you'll see the young man age to an older man. The very powerful and wonderful song and whoever's hearing this will probably never listen to Daniel the same way again.

Speaker 1

Well, I'm definitely going to check that out. So, this so this we part ways here out. I'm definitely going to check that out. What advice would you have for VCS students that are coming up into the work world and the world at large, so to speak? What words of wisdom would you have for them?

Speaker 2

I would start with love. Just don't take yourself too seriously. Don't and forgiveness is and loving one another in this world the way it is today is, you know, people need to hear messages of hope. Be that shining light. Be that message of hope you know. They're entering a world that's going to be a little more difficult than the one we had to grow up in and navigate as young adults with an entirely different set of circumstances and you know to have courage, to have strength. The things we've talked about as and realize that life is short. Gosh, we can all remember hanging out at Riccio's, you know, and Skate Place because it's as if it was yesterday and.

Speaker 1

Eastview Mall with the green rugs.

Speaker 2

Yeah. So, life is short. Don't take it for granted. Appreciate every moment, love one another. Take care of yourself. Because if you don't, you'll end up with health issues. Mine wasn't necessarily from lifestyle, but stress is something you got to manage and raising four children while running an engineering firm, I was under pressure every day of my life. And that that pressure, I prefer the word pressure over stress, but that's certainly caused in my opinion. What I had to go through so keep it light, keep it fun, and music is a great way, is a great outlet. You'll see a lot of concerts. I. I recommend that.

Speaker 1

I do too.

Speaker 2

Go dance, go dance, smile, laugh. Have fun.

Speaker 1

Yep, any final words that you'd like to add at this point, the floor is yours.

Speaker 2

No, just gratitude. Yeah, just gratitude. You know, gratitude is probably, I love the word enthusiasm. I love the word gratitude. Just multiply those, share those, spread those. I'm grateful to you. To Tom Beal for helping us set this up. And to Keith for the podcast and to you for the interview.

Speaker 1

My pleasure.

Speaker 2

To all our friends in Victor, you know what a wonderful community. What a wonderful town. What a wonderful place to grow up and to all the listeners, for if you've made it through this far, thank you.

Speaker 1

Yeah, yeah, absolutely.

Speaker 2

But I'm just. I'm grateful for life and for the opportunity to share this message of hope with people.

Speaker 1

Great, well, on that note, I want to thank you for your time. And your story and your inspiration. And being the wonderful person that you are. And I hope we can meet each other face to face sometime.

Speaker 2

Yeah, look forward to it, Tom, and hopefully your situation improves and there's remedies and be praying for you and look forward to seeing you sometime. Try to I'm hoping to get back for our 40th reunion of the class of 84 next May 25th.

Speaker 1

Yeah, I've got. I've got 35 this year.

Speaker 2

Usually May.

Speaker 1

Or 35, yeah.

Speaker 2

May and August. I'm up in the Victor area, so hope to see everybody soon.

Speaker 1

Yeah, sounds great. All right, Steve.

Speaker 2

All right, Tom, thanks for everything.

Speaker 1

Thanks for your time. I appreciate it.

Speaker 2

Yeah. God bless you, man. Talk to you later. Bye.

Speaker

All right, all right.

Speaker 1

All right. Thank you. Bye.