

Shrink Rap Radio #375
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“Transforming Tragedy Into Growth”

Dr. David Van Nuys Ph.D., aka ‘Dr. Dave’ interviews Jonathan Van Nuys
(Transcribed from <http://www.shrinkrapradio.com> by Gloria Oelman)

Introduction:

Today’s show will focus on my son Jonathan Van Nuys and his journey through the challenges of HIV and cancer to rejuvenation and a life devoted to service.

Jonathan Van Nuys, RN, MS, NP is a board-certified Nurse Practitioner who wishes to embody the values of service, to nurture health and wellness, to build community and to combat stigma and shame. He has used his own life experiences as a springboard to care for, inspire and nurture those living with HIV and other chronic and life threatening conditions. This past year, he fulfilled his dream of graduating with honors from the University of California San Francisco Adult Nurse Practitioner’s program with a specialty minor in HIV. He is currently working as a Nurse Practitioner in a challenging inter-disciplinary fellowship at the San Francisco VA hospital where he both manages his own primary care patient panel, as well as an HIV panel and an urgent care clinic. Jonathan is also currently an infectious disease consultant specializing in blood borne pathogens at the National Clinicians’ Consultation Center where he advises medical providers from all parts of the country on testing, risk and post-exposure prophylaxis for HIV as well as Hepatitis B and C.

He is also the current president of the Association of Nurses in AIDS Care, Golden Gate Chapter and an active volunteer in the San Francisco HIV community. He is an Albert Schweitzer fellow for life, a fellowship dedicated to improving the health of vulnerable people now and for the future by developing a corps of leaders in service – professionals skilled in creating positive change with and in our communities, our health and human service systems, and our world.

For his Albert Schweitzer fellowship service project, working with long term survivors living with HIV, he was awarded a meritorious service award for outstanding scholastic achievements and extensive contributions to the nursing profession. Jonathan is a long-time volunteer in the Firefly letter-writing program between healthcare students and those struggling with cancer or other life threatening illnesses. Jonathan can also be seen as a current spokesperson and cast member for the Greater than AIDS campaign. He has been featured in the *San Francisco Chronicle* as well as the *Science of Caring* journal, the book *The Firefly Project: Conversations About What it Means to be Alive* and has appeared on the web, in film, in print and radio promoting HIV awareness. Other volunteer work has included working with those newly diagnosed with HIV, serving on the board of Glide Health services, working with diabetics with mental illness and providing care at the UCSF Homeless clinic. Jonathan’s past work history includes bilingual HIV testing and work as a triage RN in both English and Spanish for many years at the Mission Neighborhood Health Center. Jonathan’s aspiration is to live up to Albert Schweitzer’s quote, ‘my life is my argument.’

Now here's the interview.

Actually I need to give a little preamble here to set the show up. You are about to hear an interview conducted by Matthew Zachary and Annie Goodman of *The Stupid Cancer Show* podcast (really, that's the name), which can be found at:

<http://www.blogtalkradio.com/stupidcancershow>

On September 23rd 2013 they interviewed my adult son Jonathan Van Nuys about his cancer experience as portrayed in the documentary titled *Nurses: If Florence Could See Us Now*. The interview also includes the filmmaker, Kathy Douglas RN and oncology nurse Laurie Mathers, whose therapeutic counsel triggered Jonathan's transformational journey. Let me set up what you're about to hear just a bit more. Jonathan came down with testicular cancer, which later metastasized to his lungs. I was conducting a weekend workshop in Ireland when he called me letting me know he was diagnosed with stage four cancer. Needless to say our whole family was alarmed by this turn of events. He moved back home with me and my wife while he underwent a very difficult regimen of chemotherapy. Unknown to us he was carrying a secret throughout the chemotherapy and a couple of years before that. We had known he was gay but not that he was HIV positive, which made the chemotherapy more difficult and risky. In the course of treatment he was referred to a nurse for an hour or two of counseling, the focus of which was that he needed to let his family know about his HIV positive status. As you'll hear in the interview, that brief counseling session was a pivotal turning point in his life. I'm hoping this brief overview will whet your appetite to hear his story in his own words as it came out in the *Stupid Cancer Show* podcast interview, which lasts about forty minutes. At the end of the interview, Jonathan and I will have a brief conversation reflecting on his amazing journey.

Matthew Zachary: Tonight's show is going to be awesome. It's all about a film called *Nurses: If Florence Could See Us Now* and was put together by an amazing nurse, two times breast cancer survivor, here in the studio live with us, Kathy Douglas. She, on her journey to interview many, many nurses around the country unscripted, came across Laurie Mathers and Jonathan Van Nuys and they're here to tell their story, kind of this epic and amazing film which keeps getting (unclear). Please welcome to the show, Laurie Mathers, Jonathan Van Nuys and Kathy Douglas.

Well, let's just start with Kathy. We had the pleasure of speaking to you briefly in our green room before the show, otherwise known as the office across the hall and really inspired by all of this and I guess my first question is, what would prompt a nurse, who's survived cancer, to start a documentary project, which I'm sure you probably invested most of your own money into, with no help from anyone, go on this masterful quest around the country to articulate and enlighten the general public to the life of nurses?

Kathy Douglas: It's an unusual question and it's not unfamiliar I think to anyone who's had cancer. I think once we've had cancer we really think about what's important and how do we want to spend our time on this planet and for me, I had gotten cancer for the second time and I thought I'd sort of learned what I wanted to do with my life but I also found myself kind of falling back into some old routines and

then I got cancer again and that took me very deep into that question of how do I want to spend my time. And I felt like, you know, everybody knows kind of nursing's a very trusted profession and a lot of people kind of have some vague idea of nurses but they don't really think about one until they need them. And that's just kind of true in our society – we don't really think about those people that are there twenty four hours a day, seven days a week taking care of people in crisis, until we have a crisis of our own. And I felt like we needed to help the public understand what the work of the nurse is. You know these are people who give a lot who deal with really hard things, every single day and so a lot of the motivation was just to bring more awareness, especially as we're in health care reform. We're changing things really rapidly and you know there's nobody that knows better how to take care of patients than nurses. So, I also wanted to bring the attention of what nurses are doing to the community and to the policy makers to help people really get connected to this profession.

Matthew Zachary: Well said, well said. And so we're going to talk to all of our guests tonight but I want to go to Laurie because along your journey you had met Laurie, one of the random nurses you found and then accosted with a film crew (laughter), hopefully scheduled in advance but Laurie, joining us tonight, sorry you missed your flight but we're glad you made the show.

Laurie Mathers: Yes, thank you so much. I'm also so sorry I missed my flight but very glad I can call in.

Matthew Zachary: Alright. So you're a nurse, you're doing your job and then one day you get this call from this random person who's a nurse saying, 'I'm doing this film, can you meet me for coffee in twenty minutes?'

Laurie Mathers: Right, right.

Matthew Zachary: So talk us through that process.

Laurie Mathers: Well it was very exciting, it was actually after I had been back to work maybe for three months after I had been off for my own cancer treatment. I was off for eight months, being treated for non-Hodgkin's lymphoma, came back to work in October and was awarded the Daisy Award that Jonathan had nominated me for. I hadn't seen Jonathan at that point for over five years but was given this award and then a few months later got a call from one of our administrative people at Kaiser saying that Kathy was making this film and she wanted to come film me. So she did come film me at my former place of employment and from that point on we decided, or she decided, that she wanted then to film Jonathan and then to film us together, 'cause we hadn't seen each other for over five years. I had a blast doing it, I just had so much pride that I could actually articulate my own experience of being a nurse and also of having been an oncology nurse for twenty years at that point and just to explain what it felt like to not only be an oncology nurse but also an oncology patient.

Annie Goodman: And Jonathan you worked in the medical field and then you were diagnosed with cancer and then you met Laurie and then you became a nurse. So why don't you tell us a little about your whole story, what you were doing before your diagnosis, why you decided to get into nursing – the whole story.

Jonathan Van Nuys: Okay.

Matthew Zachary: You were born on... (laughter)

Jonathan Van Nuys: I was born on November 8, 1972.

Annie Goodman: On a bright sunny day...

Jonathan Van Nuys: Hopefully. First of all I just want to say it's so wonderful to hear Laurie's voice. Just the story that we've had together and the connection that we've had together is incredible and it's moving just to hear you, even though you're not here.

Laurie Mathers: Yes, hi Jonathan.

Jonathan Van Nuys: My story started a little bit before I was diagnosed with cancer. I was diagnosed with HIV in 2004 and that was incredibly devastating for me. It was something I never expected to deal with in my life and the stigma of that diagnosis I really took upon myself and it started to smother me like a heavy cloak. I was very hidden about it, I did not tell my family, I did not tell most of my friends or my co-workers because I was very ashamed. At the time I was working for Kaiser Permanente which is a medical group but I was not working in the patient care side of it, I was working as a kind of project manager, arranging moves and ordering furniture and signs and felt very stuck, very trapped, working forty hours a week with this heavy diagnosis that I didn't know how to talk about. And it was two years later that I got a cancer diagnosis. I was diagnosed with stage four testicular cancer, which means that it had spread to the lymph nodes and the lungs. I had to have surgery and then go through chemotherapy and as a result I had to move back in with my family and they did not know at that point that I had HIV. I was told by my oncologist, 'you have to tell your family or you will not survive this, you will not survive carrying a secret like this.' So I resolved to tell them but then it was, I think it was Mother's Day that day I came home right before I got started with the chemo, it just didn't seem right and then things got going and more confusing and seeing the fear and the pain in my parents eyes as they saw me get ill and lose my hair, I thought 'how could I tell them that I have this other life threatening disease.' I thought it might be a slap in the face. So it was in that dark time when I was going through chemo and yet hiding half of my health stuff from my parents that I met Laurie. And I think one of the other nurses came and the whole medical team knew what I was struggling with and they said 'would you be willing to talk to Laurie?' And maybe I'll let Laurie jump in with a piece of the story here.

Laurie Mathers: Right. At that point I was actually working in the in-patient setting and just floating in and out of the out-patient chemo department maybe once a month, so on this day that Jonathan came in I was asked if I could sit and talk with him because I have a son who's about ten years younger than Jonathan and they were thinking that 'well, you know, the HIV thing,' that maybe I would have some uh... you know my son is gay, so somehow or another they thought that there was some potential service that I could give to Jonathan and just give him a listening ear. And so I sat with him and I realized 'My God, this poor young man, this beautiful soul...' Which he so is and it's so obvious that he's this lovely compassionate man, was just

deeply, profoundly, suffering from where he was holding himself, his beliefs about himself with his HIV. And it was very clear to me and painful to me as a parent and as a nurse, that he was holding something so secret that I knew would keep... he just would not, his body would not be able to deal with his cancer and its treatment and then allow himself to heal with that much emotional, psychic, spiritual energy being so thwarted. So what we did we had just this conversation where I supported him, listened to him, told him what felt true to me, which was that his parents could possibly have a reaction when they found out that he was HIV positive. If my son came to me and was HIV positive I might have an initial sense of distress around that but then it immediately would move into wanting to only wanting to help and to love and support him, that it was my feeling that that would be his experience with his parents and that I very much wanted him to know that he had my love and support to have that conversation happen. So how about you jump in Jonathan, what happened for you after that?

Jonathan Van Nuys: So I did speak with Laurie and she told me that she had a gay son and she said if he came to me and told me he was HIV positive I might initially be upset but ultimately I'd want to love and embrace and support him and I know, I see your family and I see your parents want that for you. And she gave me a bracelet of wooden beads, called Koa beads, from Hawaii and she said 'I'm going to infuse this bracelet with all of my love and support and the day that you decide to tell your parents, I want you to wear this bracelet and know that you're supported and you have a whole community of people behind you.' And I do want to interject that my family has always been loving and supportive, I never feared rejection by my family. It was more that I didn't want them to see me the way I was seeing myself. I felt like I had let them down, like I had let myself down, I was just very ashamed and after I had finished the chemo and just realized that I was stuck in this dark place and needed to do something to get out, I did decide to tell my parents one day and I did wear that bracelet and took the support of Laurie and the team of all the people who had provided me care and loved me through that period and that moment for me was a watershed moment. It released so much energy that I think had been pent up in beating myself up and that energy just expanded and released outward. I decided that rather than running from my diagnosis I wanted to turn around and fight and help other people who were struggling with the stigma of HIV and it was at that time that I decided I wanted to change my life, I wanted to go back to school and pursue nursing and become a nurse practitioner working in HIV and I was very much inspired by Laurie and not only the love that she showed for me in that moment but just how she embodied the way that one person, and that a nurse especially, can change a life just by the act of simply listening and being present and being non-judgmental and caring.

Matthew Zachary: Jonathan what hospital were you at, at the time.

Jonathan Van Nuys: I was at Kaiser. I was fortunate enough to have Kaiser insurance because I was an employee, so I was at Kaiser Santa Rosa.

Matthew Zachary: And you were thirty three at the time?

Jonathan Van Nuys: I was thirty three.

Matthew Zachary: And how old are you now?

Jonathan Van Nuys: Forty.

Matthew Zachary: God bless you. I'll be forty next May. What's it feel like? I'm approaching your checkbox.

Jonathan Van Nuys: You know it feels good, it feels great. I was terrified of forty. My whole life I was terrified of forty, when I was like, ten and then the day that it came I just felt very joyful and joyous and grateful and you know it's only a big deal until you get there and then it's like...

Matthew Zachary: So this entire show is all about young adults affected by cancer and what makes them unique as young adults and the age specificity that go along with that. While you were in treatment were you ever introduced to anyone under forty?

Jonathan Van Nuys: I was not and it was actually very tough, it was a very isolating time, in a lot of ways I felt very alone and I felt very much like I was in darkness and I didn't know who to reach out to or how to talk to anybody. I had a lot of support but I didn't feel like anybody really understood. The other people in the chemo unit were quite a bit older. Even after I finished chemotherapy I went to a support group but I was the youngest one by maybe about twenty or thirty years. Really the only person I could connect with at that time was my baby niece who at that time was less than a year old and she couldn't talk. I'd just hold her and I felt like somehow we had this understanding.

Matthew Zachary: I just wanted to bring that up because we are here raising awareness for the fact that this is an age related issue of mental health and it's not addressed through no one's specific fault. And I want to get into later on in the show the standards of where nursing is and where things are going through the lens of your story. I did want to take a quick break because I found this great list of the top ten things you'd never say to a nurse and I want to see if they're all relevant to the three of you.

'Hello nurse!'

'Do you only date doctors?'

Or, 'c'mon it's just like on TV right?'

Or, 'nurses, you take your orders from doctors, right?'

Nurse, what's taking so long?

Or, 'you can hook me up with meds, right?'

'So what do nurses actually do around here?'

Or, 'you're just a nurse.'

And finally, 'why aren't you a doctor?'

Ding, ding, ding, ding, ding, ding. (laughter)

Laurie Mathers: It's too hard to be a nurse, it's easier to be a doctor.

Matthew Zachary: Exactly. So before we get back to the serious tone of the movie, talk to us about being a nurse in the twenty first century. All three of you, yeah.

Jonathan Van Nuys: It's an incredible opportunity, I think nursing is such a diverse world. There are so many ways you can go and there's so much power in it but yes, those quotes are frustrating and as nurse practitioner I work in primary care and do very much what a doctor would do and I get that question a lot, like 'Oh, are you going to go onto med school?' It's not a continuum, it's a separate profession with its own philosophy.

Matthew Zachary: Right. Kathy?

Kathy Douglas: Well, you know, I think that nurses are poorly understood and frankly poorly represented in the media. If you look at the TV shows and that, you never see a nurse who's really empowered, who's a decision maker, who's using science to manage their practice and so they seem a bit subservient and that's just not reality. Reality is that nurses are highly trained professionals, they're very scientific and they have a lot of work that they do. It's real challenging to be a nurse today because you know we're cutting back on our budgets, we're trying to cut back on our staffing and that's a big problem. So for nurses, too many patients to care for, they can't give the quality of care that they want to. So it's a real challenge. I mean I think that we've got to get... and one of the reasons we made the film is to try and bring some counter balance to this view of nurses and what they actually do.

Matthew Zachary: Now Laurie, you were in oncology nursing before or after you were diagnosed?

Laurie Mathers: I've been an oncology nurse since 1990, so it was really my inpatient and outpatient where I've spent my entire career taking care of people with cancer.

Matthew Zachary: So let's hear your story really quickly but I do want to get to the kismet, the magic of this film, the (?) so to speak, of just the miracle that's gone on here, so let's hear your story.

Laurie Mathers: My story since, or before my diagnosis?

Matthew Zachary: Well, what were your symptoms and leading up to it? How being an oncology nurse getting diagnosed with cancer...

Laurie Mathers: Well, in retrospect, as I said at one point in the film, sometimes it just makes me laugh because it seems like I should I have been spared the cancer card given how much time I spent with people with cancer. That's how I felt in the beginning, I think that I had, as everyone with cancer I've learned has, a profound reaction to having cancer. That even if you have another diagnosis that might actually statistically be more life threatening than any particular cancer that you might have, that just the word cancer itself, it elicits such a fear response in people. I've noticed that all through my years of oncology nursing and when I was diagnosed I really was quite terrified. I had no idea how to be a cancer patient. I only knew how to be a cancer nurse. So I was in quite a bit of struggle throughout my treatment. I went into a profound depression when I was through my treatment. I did not know how to manage having had that experience. I really had no idea how to work with it. I spent

a lot of time trying to act as if everything was fine and I just went right back into my same job and ended up really causing myself quite a bit of angst, that I've now thankfully come out of and have mined the depths of how now I move forward into my life with a type of cancer that's not considered curable. The non Hodgkin's that I have is not considered curable so I am walking around with quite a depth of empathy for anyone else that is also dealing with cancer because I get it. There's no secret now. And so I'm in a place now, which is such a blessing, where when I am sitting with someone with cancer, whether they're in treatment or not, I actually can meet them where they are because I understand. Frequently there's not even a conversation to be had. I can just sit with them energetically and I get it and I don't require anybody to put on a happy face or tell me (conversation breaks up) what's really going on because I get it. In this society to have cancer there is quite a push (conversation breaks up) and I just meet people where they really are so I can love and support them through whatever process they're going through.

Annie Goodman: And this question is for everybody. I'll start with Kathy. So what made you, besides just getting the negative media and movie and television representation of nurses, I know just having been through treatment myself, my oncologist can't hook me up to an IV when I want to sit around and cry. She doesn't have time to listen because she has backed up appointments with other patients and when I just want to be cranky and complain I always complain to my nurses – the nurse practitioner, the nurse oncologist, you name it, whatever nurse I could complain to, I complain to. The ones (unclear) you name it, I'm not a great patient. What made you want to do this and how did you start from idea to what the film is now?

Kathy Douglas: Well, I think a lot of people say 'well what does a nurse know about making a film?' And I wanted to bring that up because I know we have a lot of young people on the show tonight and I want to tell you, you just got to get an idea and run with it. Life is too short, gang, to sit around and think, 'I've got to have all the answers.' I didn't have any answers I just kind of tackled the project and you know you just have to have a passion for what you want to do and a commitment to do it. I do want to say Zachary, there was an amazing group of people who rallied together to make this happen. It started as an idea and as you talk to people, you find like minded people who want to share, who want to get that same kind of idea out and so this organization On Nursing Excellence brought great support.

Matthew Zachary: You founded that, it's yours, right?

Kathy Douglas: I founded that organization. I was one of the founders of the organization. There was a whole group of us actually and we started the organization because we were worried about nurse staffing. Look, if you're going to have enough time to sit and talk to Jonathan so that you can inspire him to talk to his parents, to heal and then change his life and become a nurse and help others, that doesn't happen if you're so busy that all you can do is hand out your pills, change your IVs and run to the next room. So it's really about, if we can understand how important this work is, then more stories like Jonathan and Laurie's can happen.

Matthew Zachary: So where's the line then, with all due respect to the amount of time it takes to become a nurse, to maintain being a nurse, to sustain the literacy that you require on a day to day basis, where do you have time to be a therapist?

Kathy Douglas: You know I don't think it's being a therapist, I think that there are other professionals that are quite good at that but the ability to be able to sit down in a room and listen to somebody for a few minutes. Laurie didn't give a bunch of advice, she listened and you know something? If we're staffing our nurses so tight and we're giving them so many patients that they can't sit down at the bedside and listen to a family member or listen to a patient, then we're not living our truth. We're not living who we are or why we came into the profession in the first place. So we just have to really advocate for that and we have to help our hospital administrators and our CFOs and finance people understand that that's part of the healing process, that's what's going to help keep people healthy and out of the hospital.

Matthew Zachary: But psychosocial wellness is a new concept, it's not a new idea but it's a new concept in billables and codes and backpay and reimbursables and you guys have actually kind of been very influential in getting that to become something out of the nebulous ether that it wasn't, even five or six years ago. And it may not be a nursing thing but just something as simple as acupuncture being covered by insurance now.

Kathy Douglas: Isn't that wonderful?

Matthew Zachary: That's a huge thing. Wait until reiki is covered by insurance, or massage therapy. You shouldn't have to have an IP for a PT. You should be able to have it covered.

Kathy Douglas: You know it's coming. My brother who recently passed away from cancer was in the hospital and he could actually have an acupuncturist three times a week during his hospital stay. I mean we are making progress, I guess is my point.

Matthew Zachary: Right. So I want to come full circle to the Kismet factor which is Jonathan you were diagnosed seven years ago with stage four testicular cancer and then you had this amazing Koa bracelet that Laurie gave you as a gift of energy and healing and community and then several years later Laurie was diagnosed with cancer and... tell us what happened.

Jonathan Van Nuys: Yes, I had that bracelet by my bedside for a long time. It meant a lot to me and in the meantime I had gone through my prerequisites for nursing school. I'd applied to UCSF which is a very prestigious program, had just finished my nursing degree and had not gone back to thank Laurie, I had never seen her again. She never knew what had become of me and really the reason I hadn't gone back was out of fear. I was afraid of the smells of the chemotherapy, I was afraid maybe Laurie wouldn't remember me, maybe the people there wouldn't remember me but as time went on, I thought 'it's not about me, I really need to go back and say thank you.' This person changed my life and means so much to me. So I went back, I brought the bracelet and Laurie wasn't there unfortunately, she was out with her own chemo treatment. So I borrowed some post it notes and wrote my whole story of what I had done in the past five years, I think it was, on, I don't know, fifteen post it notes in my messy hand writing and left that with the bracelet for Laurie and I think it was close to a year later, a month later when I heard back from her that she had come back to work and received this trophy. I also, on my way out I saw a poster

for a nominated nurse for a nursing in excellence award and I thought, 'who better?' So I wrote out the story again and it turned out Laurie won that award, she won a trophy and that's how Kathy discovered her.

Matthew Zachary: That's quite extraordinary. Laurie, can you talk us through the emotional moment when you realized that Jonathan had left the same bracelet for you that you gave to him?

Laurie Mathers: Right. It gives me goose bumps and makes me want to cry just thinking about it again and I think the wonder of the whole thing for me was that I only took care of Jonathan for that one day. I sat with him for however long it took to give him his chemo, two or three hours or so and we had our conversation and then I did not know what became of him because that wasn't my regular place of employment anymore. I was doing inpatient and that was in the outpatient unit, so over the next five years before we reconnected, I thought of him many times and when I thought of him it was with a sense of 'oh, boy' I had this little pang because I was fairly frank with him and basically what I said was, 'if my son came to me and told me he was HIV positive I might be pissed, I might want to kick his you know what but then that would immediately move into love and support.' But over the years I thought 'oh, my God I can't believe I said that to that poor guy, I hope he's okay.' I worried about him. I really didn't know what happened so when I got that letter and my bracelet, I was just so thrilled and thought it was just truly extraordinary that really, not just about me per se but how we as human beings connect and can affect other people and never know it. You never, ever know how your kindness, your compassion, or the extra thirty seconds that you spend being kind to the checker at Whole Foods might completely change their life in ways that, you know I feel very fortunate that Jonathan came back and let me know but what it really imprinted on me was the power that we have to help and support each other by being kind really. By being kind and being non-judgmental, I think that's the true beauty of this story is that that interaction did change Jonathan's life and he went on and now is in a very powerful position where he has already touched many, many hundreds of lives and will continue to do that as a nurse practitioner throughout his career and his life. And that might not have happened had we not had our conversation. It's really incredible.

Annie Goodman: Yeah, Laurie, you'd be surprised. I went to my main nurse practitioner and the other nurse in the office where I was getting chemotherapy, we spent a lot of quality time together and we became very close and one of the aspects, and I'll ask all of you but I'll start with you Laurie first is, I always wonder as a patient how nurses feel and I know that when I went through treatment one of my biggest gripes, which I know that Jonathan felt the same way was, I was thirty, he was thirty-three, we both felt very young going through treatment and it was very difficult because I would have older ladies make a lot of comments to me about my age and I would get very frustrated. I know how old I am, I know how young I look I don't need you to point it out to me, I'm aware and I would sometimes go into chemotherapy and I would cry and be sad about what was going on and my nurse would always talk about how it bothered her, that it wasn't fair that this was happening to me. And I always wondered what it's like for a nurse to treat somebody, someone who you deal with regularly and you grow a relationship with, how do you... I just can't... it's hard for me to understand what it's like for nurses when they go home at night and have to think about all these patients who they have, who

they see all the time and there might be some one like me who comes in for a period for chemotherapy or there may be someone who has a terminal diagnosis and might eventually pass away. So for nurses, how do you deal with that and how do you deal with making connections with these patients? Let me start with you, Laurie.

Laurie Mathers: Well, that's a really sweet question and I thank you for asking because it makes me... How nurses feel obviously is dependent on the individual nurse that you have but oncology nurses make a choice to be working with a population that we know people with cancer die. We know that's going to happen. It doesn't happen to everybody. Many more people go on to live very long productive lives after they've had treatment but people with cancer do face a very scary diagnosis, difficult treatment and possibly a very shortened life, so oncology nurses are aware of that and what I want people to know is that we really come from the heart. Nurses come from the heart, good nurses come from the heart. They feel you, there's a deep intuitive sense that happens between nurses and patients. We feel you and we love you, we definitely love our patients. There's not a way not to love our patients. I sat with Jonathan and I looked at him and he was so vulnerable and he was bald and so young, my heart clenched.

(Phone contact with Laurie is lost at this stage)

Annie Goodman: Okay we'll go on to Jonathan to pick up where she left off. Just for you personally, especially having gone through everything that you have gone through?

Jonathan Van Nuys: Yeah, I think it's very different for me because I came in after having been a patient in some very profound ways and I want to read a quote that was very instrumental to me in starting my career and it goes:

Any of the stuff of our lives – our joys, our failures, our loves, our losses, even our sicknesses can become the stuff of service. I've seen people use anything to bless life. There is such a simple greatness in us all that nothing need be wasted.

And that's by Rachel Naomi Remen and that captures the philosophy with which I try to live my life and my career and I think when I see a patient I bring all of my own health experiences, all of my experiences, with me in the room. And whether I verbalize that or not, and I usually don't because I don't want to make it about me, I feel like that's in the room and it's just there. That dividing line between sickness and health is so thin. It's like a gossamer line, anybody can pass over it at any time and I retain that awareness and I feel like when you hear people's stories and when you hear what they walk with I can't help but fall in love with them in some way and I just want to be that person who listens and who gives them my full attention. So I think for me, it's just a profound river of empathy that is just naturally there.

Kathy Douglas: You know in the movie one of the nurses says 'you know I remember the very first child I ever took care of who drowned in an irrigation ditch.' I think that every patient we take care of becomes a part of us and you know sometimes you run into nurses who are a little cold and I think that's just because their heart just can't take anymore. It's really hard work and I think it builds up. Nobody enters nursing wanting to be insensitive but you do run into it sometimes and

I know every one of you, if you've been in health care can run into that and all I would say to you is 'try to have some compassion back' because these are people who don't deal with a crisis once in a while. They deal with it every single day as part of their career. And it's hard, its very hard work but I can't think of a patient I've ever taken care of who's not somehow a part of my being. They become apart of us.

Matthew Zachary: Laurie, are you back? We lost you for a second there.

Laurie Mathers: Yeah, I'm back. I don't know what happened, all of a sudden some British lady said goodbye and I was gone. (all laugh)

Matthew Zachary: That's the queen.

Laurie Mathers: That was the queen.

Matthew Zachary: We hear those voices too. What British lady? (laughter) We have just a few minutes left and this has been a really compelling show. We haven't done a show directly on just nursing in a long time but we do interface with nurses all the time whether it's the Oncology Nursing Society or the Pediatric Oncology, APON or actually one of our board members is the founder and chairman of the National Coalition of Oncology Nurse Navigators, Sharon Francz, so we take nursing incredibly seriously and we believe that nurses are the gateways to change for cancer survivorship and that we're not here to change physician behavior, we're here to augment the relationship physicians have with the understanding of their practice and that nurses are the catalyst for that. Social workers too fit right in there and it's really this team approach. I would ask the three of you to each spend a minute or so, what does the world need to know and need to do to improve the lives of the *effectiveness* of nurses in this country. Start with Laurie.

Laurie Mathers: Just to recognize that nurses are essential to your care and to support whatever legislation is happening to improve nursing, for example in California, the nurse ratio law that we have that is now rolling out throughout the country. There's a lot of work getting with unions and all of that to get that nurse ratio in each state legislature. That's a huge thing. So to support that, to support the work of nurses.

Matthew Zachary: Jonathan?

Jonathan Van Nuys: I think it takes being a team at this point. I actually work on an interdisciplinary team at the VA right now with nurse practitioners, nurses, LVNs and MDs and some wonderful MDs who are also mentors to me and I think and it's all realizing that we're part of a team, there for the patient, that we're all here for the patient and the idea of – a lot of places now have fifteen minute patient appointments and you can not make someone feel respected and heard, or it's very difficult, in fifteen minutes. It's like the fast food of patient care, so I think really expending that time that providers, no matter what their role be, have with patients and working together as a team and just facilitating listening to people and their stories.

Matthew Zachary: So you're not a mick nurse?

Jonathan Van Nuys: I am not a mick nurse, no. (all laugh)

Matthew Zachary: Kathy take us through, in your comments you had mentioned legislative change as part of what Americans can be aware of. Are there any bills out there, anything going through the House of the Senate, any papers being written up to improve the back end of things from the Government side for nurses in this country?

Kathy Douglas: There's a lot going on in the legislation, both state and national. I think though, in my personal opinion, is that we want to empower nurses to be able to do their work and they know what they need. We've just got to get that voice stronger and we've got to get our hospital administrators and our health care leaders listening to that voice. When you look at health care reform that's going on this country nursing's not at the table as largely as they should be. The physician's are right there but they don't understand the twenty-four a day care that the nurses do, so I think supporting nursing organizations and supporting nursing really getting out there. The other thing that I wanted to say is, when you think about what nurses mean... you know, Jonathan is one of the rare people that went back five years later and told Laurie what happened. We don't hear what happened. I can't tell you how many hundreds and hundreds of patients that we've all cared for and we never know what happens because they're discharged or they're gone and we never know.

Matthew Zachary: Are you allowed as nurses to give them your personal contact... what mechanism could a patient... I mean I'm all for this but talk me through a solution.

Kathy Douglas: So Jonathan just sought out Laurie. He went back to the place where the care was given and they were able to pass that information on. You can't really give out your... some people do it but I can't really advocate for that. But you know write a letter, sit down and write a note and send it to the hospital, send it to the hospital administrator. Make sure those guys know how much we appreciate, how much patients appreciate the work the nurses are doing and if you run into a nurse in your community as a neighbor, as a friend just pause and say 'thank you for the work you do. Thank you.' Because if nurses weren't doing it imagine what life would be. They're really the glue that holds this whole thing together. So I would just say reach out and say 'thank you.'

Matthew Zachary: Well the film is *Nurses: If Florence Could See Us Now*. I assume a reference to Florence Nightingale.

Kathy Douglas: Absolutely.

Matthew Zachary: So what would Florence say if she could see you now?

Kathy Douglas: Well you know Florence Nightingale is considered kind of the mother of modern nursing so before that it was kind of the military, or the churches or families who really took care of people in need. And Florence put science behind it and she was a real kind of advocate for nursing and I think if she looked at us now she'd be very proud. She'd be proud of how scientific nursing has become, she'd be proud of the researchers – many, many nurses with PhDs – so we've got all of that going really well for us. And a lot of people answer this question in the film so I hope

some of you reach out and actually watch the film. There's a lot of people who said 'you know, she would tell us to keep going.' We haven't solved all the problems, we're there, we're fighting the battles every day but there's a lot more to learn. There's a lot more research that needs to be done. There's a lot of areas... you even mentioned earlier areas where we're not focusing our research. So, I just think that there's... she would say, you know, keep doing this work but don't rest. There's too much to do. There's too many patients that need our help.

Matthew Zachary: So how can our listeners get the movie?

Kathy Douglas: Okay. Well, this is really exciting because as a fairly new filmmaker – this is only my second film – it's really hard for a film to get picked up by distributors but this film did get picked up right here in New York, First Run Features, one of the largest independent film distributors in the United States picked up our film. I think last month we were the highest selling film for First Run Features so we're really doing well there. Thanks to them you can rent it on iTunes for like a \$1.99, so if you don't have any money that's a great way to see it. You can order it on iTunes, you can go to the On Nursing Excellence website. It's on Amazon, it's actually in Barnes and Noble. If you Google it... I did that like a month ago, it's in, I think, fifty different distribution channels, so whatever your favorite place to purchase films is. I want people to know that when you purchase that film, this is a non-profit that this money goes to and that helps further the work of this group of nurses that are trying to really make a difference. So we think of it as a donation in a way so thank you so much. If you rent it or your purchase it, it really helps the work go forward.

Matthew Zachary: It was off to a rocky start but this was one of our best shows. It was really compelling, really emotional and it's exciting. I remember my nurses, Annie mentioned her nurses, they were the glue, they really were the glue. I had great care but I too was isolated. I was diagnosed during Clinton so there was nothing in the world of wellness, it was just cut and dried, get you out of there, meat factory mentality. I don't fault 1996 for being 1996 but the whole reason I started this organization ten years later to the date was because it's not okay that I went alone and it's not fair that even seven years ago, you went alone. People go alone today still, so I would believe Florence would say, what I always say, that we've come so far but behind every door of success are ten more of challenge and we have to pursue and do our best and make the most. So you guys have been really awesome. Any follow up thoughts Annie?

Annie Goodman: I have to say I love nurses, they are the ones... I have a lot of friends from College who are nurses and they're the ones who I would hit up at all hours of the night, texting, calling, giving them my laundry list of side effects from chemotherapy and 'I haven't gone to the bathroom in about twelve days, what do I do?' They were the ones who answered the calls, answered the texts. It didn't matter if they were in on oncology, if they were... one of my best friends is a nurse and she's done a little bit of everything. She hasn't done oncology because as you all know oncology is difficult and it's just not for her but she looked into a lot of what I was dealing and the drugs and was very, very helpful but my nurses were the ones who gave me their cell phone numbers and their email addresses and it was 'I just passed out with my friends do I need to go to the hospital?' She responded in fifteen minutes so I knew... and it was a weekend and I knew what to do and even my mini

meltdowns, six months or whatever, not even six months past treatment but just my mini meltdowns of 'help!' And I wasn't even their active roster of chemotherapy patients but I just was having a meltdown on a weekend and needed to talk to somebody and I didn't want to bother my oncologist 'cause I was like 'she's not going to... I don't know if she's going to respond on a Sunday and she called me and nurses are very helpful. They're the best with veins, they know how to put in a good IV. They know which veins to leave alone, even almost a year after chemotherapy... I had two main nurses, one of them knows, 'don't go near that one.' It's seen about a hundred wars. But you guys do very important work and you guys and you might not think you're therapists but you are and even when you tell us that we need therapists, that's you being a therapist.

Matthew Zachary: Well said by Annie. Well said, well said. Well, once again, so you made the trip, first of all, it's a schlep, it's a big trip. Thanks for coming up to New York, enjoy yourself while you're here, we'll give you tourist tips after the show. Laurie are you planning on still coming 'cause we'd love to see you if you're in town?

Laurie Mathers: I'm not able to come. I'm actually dealing with my mother who's really sick and I'm sitting in the parking lot of the hospital now as we're on the phone.

Matthew Zachary: Okay, well we won't take up much more of your time, go be a caregiver, go be a nurse. Again thank you guys so much. The film once again is *Nurses: If Florence Could See Us Now* on iTunes, Barnes and Noble, Amazon, you name it you can find it anywhere. Thank you guys: Laurie Mathers, Jonathan Van Nuys and Kathy Douglas. You guys kick ass. Thank you so much.

(End of Stupid Cancer Show podcast)

Dr. Dave: Well, I have Jonathan here with me now. Jonathan welcome to the Shrink Rap Radio studio.

Jonathan Van Nuys: I'm so honored to be on the show, you know I'm a fan and I'm honored that you're proud of me to want to feature me.

Dr. Dave: Oh, yeah. We have a mutual admiration society going here for sure. I wanted to get you on the show live before sending this out into the wild. We heard your interview on that other podcast but I really want people to get a sense of your voice here. So, we've heard your story, to summarize a bit, what's your big takeaway from your confrontation with life threatening illness?

Jonathan Van Nuys: Well, first of all I want to say that I would not wish life threatening illness upon anyone. It's not a desired vehicle for growth but I've been lucky enough to be able to use what I thought was the worst thing that happened to me into a springboard into a new and meaningful life and so I think my takeaway is resiliency and gratitude, that sometimes when you're struggling through the darkness, you can find these moments of light, you can rediscover how much love and support you have in your life, how many people want to be there to hold you and use those struggles to find a way to give back and to really take the time to be grateful for life. I want to say the year after my struggle with chemotherapy and illness, which was

2007, when I started regaining my health, that feeling of losing your health and then having it come back when you weren't sure that it would, was so joyous. I remember you took me to Hawaii that year as I was just recovering and I felt so happy and joyous, the stars were sparkling and just to breathe and walk and be alive and for a year I was really glowing with that awareness. And I do want to say, it's difficult to retain that awareness in your everyday life as stress hits you but I try to reconnect with that as often as possible and I do think it still lives inside me.

Dr. Dave: Yeah, thank you for reminding me of that trip to Hawaii. I had kind of forgotten about it but I remember, I think we saw fire dancers and there was this kind of impromptu gathering on the beach that somebody took us to and I remember that you and I had a special moment of conversation about 'okay, let's imprint this on our brains.' Fortunately you did imprint it on yours (laughter).

Jonathan Van Nuys: I remember it well. For me it was a relaunching into life. That's the moment I remember of really feeling like I was reengaging with life, my health was returning, we got to go with my sister and her husband and my niece who was quite young at the time and who really was a presence that helped me through that dark time.

Dr. Dave: Okay. Now maybe you've already touched on this a little bit but what do you want to say to listeners who might be struggling with serious illness themselves?

Jonathan Van Nuys: Again, I want to express my empathy for anybody going through that. It's quite difficult and I don't want to minimize it in any way but find what support is out there for you, whether it be your family, whether it be your friends, whether it be in your health care providers, or your neighbor. I think there are a lot of people that surround us that want to give love and sustenance and life and to really find that. To find those moments of light that pull you through the darkness. For me there were different writings that helped me through, like Rachel Naomi Remen for one, Thich Nhat Hanh. Another thing that really helped me through was my eldest niece, Ella, who at the time was my first niece and she was a baby, less than a year old, who couldn't talk and I was having such difficulty articulating what I was going through that it was really a connection to life and an anchor just holding that baby who didn't need me to talk, who just was pure love in expression. So finding whatever those things are for you to anchor you and to pull you through and to give you some sort of meaning and hope. Because there is hope and I hope that I'm an embodiment of that. I, again, would not wish cancer on anyone but for myself being lucky enough to have survived it I'm actually glad that it happened to me because it gave my life a new direction and meaning and I could not have kept going in the vein that I had been going previously. It really helped me find truth and openness.

Dr. Dave: Yeah. Well you talk about the cancer, what about the HIV part because I think many people would find that so overwhelming, how's that working out for you?

Jonathan Van Nuys: It was so overwhelming and cancer is in a lot of ways, a very socially acceptable disease, whereas HIV is not and that was tough for me at the time because I was really hiding that secret and for me finding the courage and the support to be open about that has been life transforming and now it's become my focus for my career and my life, helping others struggling with HIV, helping others who are

struggling with that stigma and shame. It's been such a journey for me. When I think back to that time when I was hiding my pill bottles and hiding the secret I felt very closed down and almost monstrous and twisted inside just to be so hidden. When you have no secrets and you're open, it was such a relief and such a burst of energy and now my whole life has been transformed. Now I'm working with people on their journey with HIV and I'm a spokesperson against stigma working now with the Greater than AIDS campaign and I'm on a billboard speaking out against stigma.

Dr. Dave: Yes, you are. Talk about being courageous. You're really out there. I wish I had a picture of it to maybe put on the site but I want listeners to know that he's on a huge billboard.

Jonathan Van Nuys: Yes, so it's been quite a journey, literally and I'm just grateful for every part and for all of the support that I've received on that journey because I think nobody gets through illness, or really anything, alone. We need community, we need family, we need love, we need support and I encourage people to seek that out in whatever form that they can.

Dr. Dave: Well, Jonathan I feel privileged to be your father and to be a witness of this journey and it was difficult, much more difficult for you than for me but difficult for me too and so I'm really glad to be able to share you with my Shrink Rap Radio audience out there and also really appreciate that you are a big listener of the show, more than anybody else in the family.

Jonathan Van Nuys: I am. I love the show I always learn so much from it. I'm honored to be on the show and I'm, of course, very grateful to have you as my father. I really see my family as the ground of my being and support and I could not have made it to this point without the support of my family so I'm so grateful for that.

Dr. Dave: Well that's a great place for us to wrap it up. I'll use my usual close, Jonathan Van Nuys thanks for being my guest today on Shrink Rap Radio.

Jonathan Van Nuys: Pleasure's all mine. I'm honored.

Wrap up:

Let me give another plug for the film that features Jonathan's story. The name of the film again is *Nurses: If Florence Could See Us Now* and of course that's a reference to Florence Nightingale. The title makes it sound kind of boring. I was willing to watch it because my son was in it. Actually I found myself engrossed in the whole thing, well before Jonathan's part, which comes near the end. Nursing is a far more diverse and activist profession than I'd realized. Jonathan's going through the RN and then the Nurse Practitioner program has also given me insight into the profession. Having been to two of his graduations, I've been impressed by how warm and loving the faculty are. I have to say this profession seems to embody the qualities that I associate with the humanistic psychology movement. I think in part that's because Carl Rogers taught in a nursing school or two for part of his career and I think he had a big impact. Back to the film - it's not a boring documentary and I think you'd enjoy it even if you don't have a son in it and no, I don't get any kickbacks for promoting it

here. You can add it to your 'save' list on Netflix or you can buy it new on Amazon for about US \$17.

Thanks to today's guest Jonathan Van Nuys for sharing his journey and to the Stupid Cancer Show podcast for allowing us to use their interview with him