

Ethan Masselli & Kailyn Braley
Tom Antonik

Ethan: Alright so, my name is Ethan Masselli I'm with USM. So we are doing this recording for the Sampson Center. Its E-T-H-A-N M-A-S-S-E-L-L-I.

Kailyn: My name is Kailyn Braley it's K-A-I-L-Y-N B-R-A-L-E-Y.

Tom: And I am Tom Antonik T-O-M A-N-T-O-N-I-K.

Ethan: We are in Bowdoinham on November 17 its 2016. Alrighty, so we're going to start with some background information: where are you from Tom? Your parents names, and kind of the beginning of your life really.

Tom: Ok well, I was born in Miami Beach Florida, something I don't let a lot of people know, but my brother was born in upstate NY, my sister NJ. My father was in the service so, um, so both my parents were from NJ, both, all their parents were first generation immigrants so my mother did not actually even speak English before she started school because they were in such a sort of tight knit you know Polish Russian community. But as a child I just sort of knew moving around a lot but one of the things i did not appreciate as much at the time that I did afterwards, there were three years that we lived in France from the ages of seven to ten but most of the time we lived in Maine. Before that we were stationed in Bangor when that was an Air Force Station and then in Topsham which the navy eventually took over. And then my dad retired from there, and then when he retired we moved to Lisbon Falls which I refer to as my therapy years because those were the years I sort of before my last year of junior high and just going into high school so I think with an awareness of my sexuality and a very um small dying mill town with homophobic overtones. It was yeah, not my happiest time of my life I mean there are many things I enjoyed and, probably in many ways wanted to deny my gayness and certainly wanted to kept myself very closeted there. So mostly grew up in Maine, time in France went to California shortly after bailing out of college for about it lasted about 6 weeks. I was so unprepared the University of Maine in August. Went to live with my brother and some of his friends out in Santa Barbara turned out to be a total failure and again part I think because of my sexuality I was at the time the drinking age was 18 in Maine but I was 21 in California so I couldn't go to a.. I was 18 when i moved out there so I.. the only way I really knew how to perhaps connect would be through a gay bar and I couldn't there was a gay lesbian organization at the city college where I took some classes it was practically needed a password to find out where they met and I think I was so nervous about being found out by my brother and others that I never really came out there but I was certainly aware of my sexuality. But I think it led to a lot of loneliness and isolation. Eventually moved back to Maine took some odd jobs here and there and then decided to go back to school and that's when I went to the

Miami Beach, FL
Upstate NY, NJ
Family: Father in service
- 1st generation immigrants
- Polish Russian

France

Banger, Air Force
Topsham

Lisbon Falls

Junior High / High School
Awareness of sexuality
Homophobia
Life struggle: Deny gayness /
Closeted

California
Education
UMA
Santa Barbara

Gay Bar
Closeted

Gay and Lesbian organization

School of Visual Arts in NY and... 1979 left there in 1988. That was a very pivotal time in my life it was also the time where you first started hearing about these strange diseases that gay men are coming down with. Coming in at sort of the end of the sexual revolution even though I was, I felt myself you know very shy sexually and socially. That was during a time that I was in a long term relationship that we started hearing about these illnesses and probably stayed in that relationship much longer then was healthy because I think I was just too frightened to have to go out and I didn't know how to date anymore, how do you negotiate safer sex? It was there that through a, I decided to take part in a study through Columbia University on the psycho-social effects of gay men on this illness that was happening quote-on-quote healthy men. I think the 3rd year into the study they offered if you wanted to they could provide an HIV test. I think when we started the interviews I don't think the HIV test was even available. So, um, I opted to do so but chose not to get the results right away I thought well I've been in a monogamous relationship for what felt like 350 years but I think that's 3 and a half years, times bad relationship years, similar to dog years. But after my partner and I broke up you know another year or so I'm never gonna date anyone ever again! I was somewhat beginning to get interested and I thought I would go find out the results and um I think I was, actually, I was quite shocked that I was HIV positive because I did not consider myself as much at risk as many other people I knew. I certainly, I was at risk, it was, it was a shock and at that time there were no treatments whatsoever. I think it was only within the year following that it was almost exactly a year to the day of finding out that I was HIV positive that I discovered I had Kaposi Sarcoma, which confirms that I had an AIDS diagnosis that AZT had just become available and it was outrageously expensive. Doses that they were giving were quite toxic so I had to sort of juggled you know getting \$800 here and hope my insurance would reimburse me by the next two weeks... I forgot how, maybe it was \$800 a month I forget I think that's what it was at the time maybe get two weeks at a time and hope my insurance would you know as I said get the check back so that I can get the next two weeks. Yeah, it was a very... um... it was a scary time it was also kind of an amazing time as the activism, that rose up out of it. I was pretty politically apathetic before I had started going to the People With AIDS Coalition after I was diagnosed with AIDS and again I remember you know walking around the block three or four times before daring to set foot in there. Just kind of taken aback by the wide variety of people who were there, from men into leather, to drag queens to just a whole gamut of, you know, this you know the different facets of NY and gay male, mostly gay male side, I think there were a few woman there. Really kind of found a sanctuary there and thought I would eventually maybe try to give something back so I, oh I thought you know maybe you know volunteer there in the kitchen or something and someone said, oh you know there's openings on the board of directors. I'm going, I.. me.. you know I've never. So I, I put my name in and I mean there was I think I'm on board at the time with Michael Callen and Griff Gom. What was Saint Vincent's now I think the Callen Ward Clinic in NY is named after Michael Callen. He was just an amazing activist. But I got elected onto the board and I think

Education: NY School of Visual Arts
AIDS

Shyness

Longterm relationship

Frightened

HIV test

3 year monogamous relationship

HIV test results
Shocked at being positive

No treatments

AIDS: Kaposi Sarcoma
AZT
AIDS: Expensive meds

Scary time

Activism / PWAC

Shyness

Variety of gay men
Sanctuary

Volunteer

Michael Callen / Griff Gom /
Activism / Activist

Elected to board

that sense of just by virtue of telling my story and experience that I make a difference was both kind of shocking and empowering to me and along with that started doing some speaking engagements about living with AIDS. So the very first one I was asked to do was at Parson School of Design Fashion Institute yes the Project Runway long before Project Runway. But I think what got me through my nervousness about the day before wasn't what was I going to say, but what am I going to wear? I've got to find something very stylish, very nice, pink bouquet type sweater, simple black jeans. As often as I, with these speaking engagements like some of them from Gay Mens Health Crisis, would go and speak about the statistics and how you get it and how you don't and then I'd share my personal story and the silence and the wrapped attention that I got when, again, just telling my story overwhelmed me and the honesty of the questions, things I hadn't thought of. They're in a fashion industry, they're working with pins and needles, what happens if someone sticks their hands in a thing of pins? You know, these are things I hadn't thought of before. I found during public speaking very healing and particularly as I started losing a lot of people and did some grief work particularly with the Elisabeth Kübler-Ross Institute one of the ways of grieving is telling your story over and over and over again and I got fresh audiences. I get someone else to tell its like, "oh god now Tom's gonna tell his AIDS story again". I think being able to tell my story in public places and make them real for people was very important for me and it felt like i was contributing to something.

Public speaking about AIDS / PWAC

Parson School of Design Fashion Institute

Gay Mens Health Crisis
Sharing personal story

Public speaking healing

Elisabeth Kübler-Ross Institute
Grief work

Ethan: It was the School of Visual Arts that brought you to NY right Before your diagnosis what was the community like within NY when you had just arrived?

Education

Tom: For me it was very exciting in a number of different ways certainly in the freedom to be openly gay in many parts in NY. There's still certain areas that I'd be careful. There were incidents of some pretty severe gay bashings in the West Village at the time. In many ways one of the great gay meccas but it was, there were still risks involved there. As an artist it was a very exciting time with what was happening in the art world: galleries, artists rising. For me, for I think, both those reasons, just the freedom to be openly gay and just, you know, what was popping up. The art world was just tremendously an exciting time to be there.

Openly gay in NY

Risks of being gay: Gay bashing

Art
Freedom to be gay
Exciting time

Kailyn: Where were the best places to hang out and be open?

Tom: Either the West Village or the East Village I think at that time there were places in NY that sort of had their different flavors. Some bars on the Upper West Side that I want to say were a little bit more preppy. There were some pretty dingy places both on the East Village and the West Village. There was one in the East Village I really liked a lot that was really very much a neighborhood bar but you know people like Edward Albee would show up every once in a while. Some famous people who were well known at least at that time in the gay community living in the East Village would pop in and just sort of low level. Then there were some rising, you know, sort of alternative types of bars rose up in like Avenue A and just some interesting

West Village / East Village

Variety of bars

performances. Punk was sort of blending in, Wigg Stock was going on a lot of different places. But, I think also for my personality type, you know, I tell people I don't like crowds, they say, "You lived in NY for all those years?" There are also these amazing sanctuaries like the Frick Museum and the Museum of Natural History as well the Metropolitan Museum of Art and the parks. I found NY to be a "neighborhoody" type of place, much against what I heard about it being a very cold indifferent place, if you were known in the neighborhood it was just like having that common hello with the shop keepers and kind of knew the people in the neighborhoods. But I would say there was a great deal of my student loan money that went to a couple bars in the West Village piano bars there that benefited greatly from my financial aid.

Ethan: So what was it that got you involved in the arts? It seems like its something thats been a part of your life for a while.

Tom: Well I think I always had a gift for drawing I think as well as expected of me and I think that's one of the reasons that I've sort of had this push pull with it and when I bailed out of the University of Maine at Augusta besides being really unprepared for college it was just like, "Well, Tom's gonna be an artist" and I thought, "Is that really what I want?" So I think it took about another five years of working odd jobs here and there before deciding it was my decision. The first school I most wanted to go to was Rhode Island School of Design and I did not get in and I was pretty disappointed with that. Unlike people today who you know apply to 20 schools, I applied to two. About 5 years later I applied to one, again School of Visual Arts and I was able to get in. It was partly I always loved NY and there was also an illustrator who was teaching there who's work I admired a lot and some other names that I didn't know well but recognized so I knew that they hired people who were professionals in the field. I think the um.. back to the earlier question it was almost always expected of me and I think again I still sometimes push back on that you know, "What if I wanted to be a doctor!" I was gonna say engineer but no, no, I don't think I could do that. I'm not good with math, but you know, there were plenty of other things I was interested in. I actually went back to school a number of years ago and got a masters in Theology and someone said, "What are you gonna do with that?" and I'm going, "Do somethings with that?" I actually had no plans to do anything with it, it was just because it was something that fascinated with me on, and also how to sort of interweave the arts and spirituality. I actually had gone out to live at the San Francisco Zen Center with the idea that I might be there for two months or twenty years I didn't know. If I got California residency then I could perhaps do graduate work for a lot less money. So I went down to the library and I got the catalogue for the San Francisco State College, I think the course listing looked like about the size of the Manhattan phonebook, and I think I got like kind of overwhelmed at that point. Decided to come back for the summer thought I'd take a course or two at Bangor Theological Seminary campus in Portland and they said, "Well you know, even though it's past deadline we could get you enrolled if you want." I'm going like, "I don't know how I'm going to pay for this" and one thing just sort of

fell in place after the other. Within the first week I was in class 9/11 happened and I thought this is really where I need to be because how is it that people can do such wonderful things in the name of religion and theology, and such horrific things, and so I wanted to dive into those questions. Not that I really ever found the answers to them but I think it was still the right place for me to be.

Ethan: One of the things that, moving away from the questions for a second, I think one of the stigmas sometimes with HIV AIDS is this idea of promiscuity, or you know deviance and all that, but your story is quite tame so far. This idea of shyness and the arts and theology. What was that like for you kind of going through that transition of shyness to diagnosis to actually thriving on talking about your story? Were you aware of that transition or what was that like?

Tom: Well yeah and I'm still shy and I'm still very much an introvert and some people and it is an anomaly that I'm so comfortable doing public speaking. So are actually a lot of actors who are very introverted and shy. But the public speaking opportunities are a very defined role I go in I'm speaking about something that presumably I'm an expert on, it's my life, so you know, as long as I haven't made things up along the way that everyone is gonna check on. I can be pretty consistent with my story, sometimes I'm asked questions I've never thought of and are just illuminating to me. So maybe the surprise was taking such a public role but I think still remain very much a private person. I think there was a piece of speaking it would sometimes bring attention to the word promiscuity because I'd often had connotations to it. And I said one definition that I heard was, "Anyone who is promiscuous is just someone who has had more sex than I've had." I think there was just a very short flash of going, you know, I've known people who were in the baths almost every night and came out almost unscathed. And again, someone who is relatively shy and when I was in relationships they were monogamous relationships, you know, I became infected and I almost instead of going to, "Why me?" it was, "Well why not me?" Reminded me of a story of running into a friend of mine at Hannaford's, we were both in the same support group and he was doing quite poorly and I asked him how he's doing and he said, "This is going on and that's going on, Tom you know I've had this for like a year and a half and you've lived with it for five years and you're doing so well its just not fair!" and he stopped himself and he said "I'm sorry, I'm sorry! you know, I'm really glad you're doing well" and I said, "No, you know, you're really right its not fair, there's no fairness about it."

Kailyn: How were relationships and how was the community like for you after you were diagnosed?

Tom: Slowly it took me a while to tell people and I realized I had to do it in stages because it was often I had to take care of them as I was telling them I think they were so much in shock and concern for me that I needed to stagger how I told people. I think for the most part people around me were pretty supportive. There were some clear instances of AIDS phobia

that I experienced. I never told my mother, she um, I did tell my father, my mother was not doing well health wise and he asked me not to tell her and I did not know if that was the right decision or not but it made an easier one for me. She died about, she died actually the very night that I moved back to Maine. I often said before I don't know if she knew but I always suspect she suspected because mothers always have a way of suspecting things and my father was also very hard of hearing and spoke very loudly on the phone and my mother had impeccable hearing. The night before I was coming home I had said something and he said, "Well don't worry I didn't tell your mother that you have AIDS." and I'm thinking you might've just now. And she died that night.

Ethan: It almost sounds like telling people that you're diagnosed was almost like coming out.

Tom: It is very, very much coming out.

Ethan: In terms of coming out, what was that like for you? When did that happen in your life?

Tom: Coming out as gay or coming out as...

Ethan: Gay, yeah.

Tom: Well one of my first summer jobs was in Ogunquit, and so my dad was working in Biddeford at the time and I was mentioning about my summer job in Ogunquit and I really didn't know what was going on in Ogunquit but my dad's secretary said something, "Oh you've gotta watch out for those people there." And I'm going, "What is she talking about?" But then going, "Hmmm, I wonder..." It still took me a little while to come out but it was certainly an inviting place to come out so I gradually came out there. Publicly with my family and my friends and my sister/ I think my mother always suspected actually took my father by surprise but in some ways my father was more accepting. My mother, I think looking back had some mental health issues, varying shades of clinical narcissism, so that, it was sort of alright that I was gay, but don't be gay in front of the neighbors. I always felt like there were multiple standards depending on who's around. She professed acceptance but you know if the neighbors were there then don't say anything about it. That felt hurtful. I think it was easier being out in NY, and that was about the time being in Ogunquit. Coming out in Portland I think at the time the bars but most of the time I was at the Phoenix which curiously had been a Quaker meeting house and I actually become very involved with the Quakers later. And so I think that's where a lot my coming out experiences were in Portland. I think unlike many people I knew who were also going to Boston I don't know why Boston had the same appeal, I guess if I wanted a city I wanted a real city, so I'd go down to NY every once in a while, the night life and the rioty and the diversity of NY was just very exciting.

Ethan: How old were you when you started working in Ogunquit?

Tom: Lets see... Seventeen cause I actually graduated High School when I was 17. I had just started college when I was 17 just cause the way my birthday fell. Yeah so 17, for about 5 years, probably the first couple years still pretty closeted but still very intrigued by what was going on.

Kailyn: Did you know a lot of people who were gay that you went to school with?

Tom: No, not really, I mean there might've been one or two who presented as gay and I think later on I found out were and I think in some ways I might've avoided them because I was afraid of that association. There was one person I had such a major crush on and he went and joined the Marines and I saw him come back afterwards and boot camp and even more of a crush on him. Many years later did I find out that he was also gay. One time we were both tripping on acid in my parents house sitting, I think, on the bed in my brothers bedroom or something and he said, "Remember that time we were trippin' our asses off sitting on that bed, why didn't we tear one another clothes off?" And I just want to bang my head up against the wall if I had only known! But he also, you know, he hanged a lot of his friends were a bit of a rough crowd and I thought if I made that mistake if I called it wrong it could be very dangerous. Missed opportunity!

Ethan: Before we move into your transition back to Maine I wanted to know, are there any other stories that you thought might be interesting of your time in New York? Either... most likely before your diagnosis just, kind of just, like, what life was like there, right? In New York during the 80's, I suppose, when it would've been right?

Tom: Yeah, yeah, I moved there it was in 1979 so I think it was 1988 when I left. Studio 54 was going on, I never got in (laughs). Walking by a bistro in SOHO and looking in and seeing Andy Warhol and some other people around a table and my friends would say, "Lets go have a drink at the bar." Eavesdropping in, and he was actually tremendously boring, he was usually quite boring from what I understand. He had a lot of very pretty people around him. But, you know, often just walking by different celebrities and it was just sort of the protocol in NY that you gave them their space. I remember seeing Torch Song Trilogy with Harvey Fierstein when it was the 64th Street Playhouse and they were passing a hat around to keep the production going and they eventually moved it down to off Broadway at Actors Playhouse on the 8th street and the West Village. In between acts getting back to my seat I'm sort of doing this shift with this guy I thought, "He's awfully cute." And then later on in the scene I realized it's Matthew Broderick who was playing the young boy that they adopted in the play version. I remember seeing Luth Gordon in Central Park. And I did I actually write Harvey Fierstein a note saying that I really enjoyed his play and I had an exhibit of my own work at the School of Visual Arts my senior exhibit, I said wanna come down and see it sometime I'd love. He actually wrote me a note

back and we had a mutual friend and at one point I went and looked at the guest book and there he had signed it put his little bunny rabbit sort of his insignia so he went to see my show. We had run into one another a couple times and just chatted but he was very very sweet. I think I mentioned my last boyfriend was Vito Russo who was who wrote *The Celluloid Closet*. I met him we were at the People With Aids Coalition and I wasn't aware of who he was we just sort of kinda hit it off started makin' out and before I knew it we had our regular nights together he was very active with Act Up. My People With AIDS Coalition meetings were on Monday his Act Up meetings were Tuesday or I forget... anyway Thursday was the free day so he'd have movie day at his apartment and he'd show me these videos he had from when Bet Midler was in the baths and talking about these conversations he had with Lloyd Tomlin before she came out and some of the guests would leave and I would stay. He was such a fiery, passionate activist but personally one of the sweetest men I knew just really treasure, treasure that time. I think neither of us were each others great loves but I don't think I liked anyone more then I really liked him as far as partners, I just liked him. Times when he was beginning to fail coming up behind me and comforting me with his hands on my shoulder cause I'm worried his heath was failing. And he had an opportunity to have lunch with Elizabeth Taylor and he said he was so impressed at how knowledgeable she was about all the various AIDS drugs that were coming up. He said, "If anyone ever makes an Elizabeth Taylor joke in front of me they have to hear from..." so second hand that. He had on his coffee table his picture with Elizabeth Taylor. My two degrees of separation with Elizabeth Taylor. It's such an odd shift of gears form that time of sexual freedom and expression to agonizing arguments about do you close bath hoses? Protests by Act Up that were effective but sometimes pretty offensive to some people, so it was such a shift from such a free spirited place where it was one of the gay friendliest places in the world to one of the epicenters of the AIDS epidemic and activism and a whole change of gay culture. And also, just the horrific compounding of grief. I think after I moved back to Maine a couple times I'd go down to NY, after a while I stopped going because I used to continue to go quite a while but I'd look down a street and go, "Thats where Vito... no, he's not alive anymore. Oh that's where! No.. they died a couple years ago." You know I'd look down different streets and, you know, think oh yeah, that's where so-and-so lives... just reminded of all the deaths.

Ethan: You had mentioned a partner before when you had taken the HIV test and you had said you stayed with the partner longer then you probably would've out of fear, was that Vito?

Tom: No, no, no that was someone else. No, um, Vito was, he knew, we both knew our status but the partner I was with was before we knew anything about HIV/AIDS, it came into an awareness while we were together. As the relationship was deteriorating I was just... it felt like if I leave this relationship, again, I don't know how to negotiate safer sex, not sure, do I want to get tested? The whole dating world had changed from that time. But no, that was someone else. At least presumed on my part, you know, was in a monogamous relationship I know he had had

multiple partners before we had got together. I had heard through the grape vine that he had tested and tested negative which I guess was false information. So I did not tell him when I found out I was HIV positive, we were not on the best of terms. But when I was diagnosed with AIDS I really wanted him to know so I called him up and tried every ruse to have him come over, and basically I'm a really terrible liar and he was going, "What's up, what's up, what's up?" and finally did what I didn't want to do and told him over the phone so when I was telling him over the phone I was basically telling him he was likely positive as well cause I found out my information was wrong and he had chosen not to get tested. I think long after that he developed symptoms and actually I think died within a year and a half.

Kailyn: So, earlier when we were talking upstairs you said you took up photography because you were, you thought you were gonna die from the virus. When did you realize that you might actually live?

Tom: I was living in Portland so I wanna say I don't think? Maybe in the last 8 or 10 years, slowly got back to it. Still had a dark room set up in my apartment in Portland so sort of going back and forth with photography and painting and I moved from Portland, I wanna say its been, I think, its been four years since I've been here, four or five years since I've been here. But I think I was slowly moving towards doing some more painting. Um, not too long ago. But I've done you know painting here and there, that um and then go back to photography, and then painting here and there and I think very gradually um trusted that um it didn't seem imminent through the uh HIV AIDs. So I mean, its hard for me right now to figure out the dates, it was just more of a gradual, um, I think, you know, its you know, in a similar vain, he is the same physician since I moved back to Maine and I think at the time there were only three physicians treating people with HIV AIDs and um , and IM very fortunate for you know, having a very good report with the physician I had, and when I had to start dealing with you know, regular aging stuff, Im like hmm didn't think it would come to this! You know, Oh, boy! Colonoscopy! (Laughing). Yes, so, HIV is fine Tom! Look at your cholesterol! So, um, and um, and it, I think in some ways, um, I remember I think before the uh, the triple combinations and the um combining the protease inhibitors they um, balancing now, reverse transcript aids inhibitors. I thought, you know, I had been doing so much work to get ready to die if there were suddenly a cure I wouldn't know what to do with myself. I and I think that happened in a, in a much slower way because I was doing all sorts of emotional, spiritual, and practical work you know, making sure my wills were in order, my medical attorney, and then um, I kept on living, and you know, at one point, um as part of that, early on I went on disability. again thinking that Id probably have a year in half to two years thats what most people had with my particular set of conditions and my p cell count, and um, so, I found myself in a catch twenty two position as I you know, started feeling better once the protease inhibitors started working for me. If I went back to work, I would lose benefits, um, and there have been times when I worked part time but for whatever I report, you

know if, four dollars, three dollars gets taken away, and um, and the benefits um, for awhile I was working at the Portland Public Library shelving books. Its just...I love libraries. I love books. Um, and its a minimum wage job and I have to make sure that Im not making under or over, cant make more than a certain amount, but yah, I figured out once, you know, I was, from what got taken away from my benefits by my reporting that I made, I was making like three dollars and fifty cents an hour, I said well you know I might as well volunteer. And and I did for a while, work helping a man with MS and that paid better but I was um, really didn't get me ahead much financially, um cause of what I would lose. I had to be really careful putting in extra hours in less i go over a certain amount and put my social security and disability at risk. So um... so you know, at a certain point, um, a job offer came up in Pendle Hill, which is a Quaker, study center outside Philadelphia and the woman who taught the art program part of that was retiring and she started created this wonderful art room with twenty four hour access and kilns and um, looms, and you know frames , you know, I just... my sacred space. And, um, and I thought well what am I going to put on my resume? You know, I had started, actually started teaching at school of visual arts um even before I got my, starting to work on my Masters, to stepped into, start teaching first by substituting and then filling in for some instructors on sabbatical, understanding that Id work towards my Masters. Then I really loved teaching. Uh, heres a, once I decided id needed to go on disability and move from New York I sort of left that behind. You know, all these years of no work, um, .. I think once I put together all of my volunteer work that I had done, Id hire me. Um, and and you know really, what was I think tremendously helpful for me to see what I had been doing even though I wasn't getting paid for it, and if I find that I did not get the job and at least I was one of the finalist I think. Interviews, I felt good about that. Um I think that started my long story of , you know, very unusual relationship with Martel and with having spent a lot time, you know, preparing to die, and then what do you do when you keep on living and you know, whats my retirement fund? Yeah, uh, hope my partner remembers me in their will (laughs). Um, You know, no retirement fund, no investments, no, its um... so I think um, this last September turned sixty and so a major milestone for me, thinking I outlived AIDs, and I outlived, you know, two bouts of cancer related to AIDs, I outlived depression which I think is still something that could take me. Um, Ive had a lot of falling strings with some dark depression including suicidal ideology, ideations, um, I but you know Im thinking about old age, so you know maybe I started, you know, been pretty lucky with the HIV, and you know my doctor he says you're amazing Tom, he really means it... um but now, having to make choices of where do I focus my energies and what can I give up to, and um theres a piano keyboard up there and I will never become proficient at it... so (laughs), I um, yah, do I want to spend more time just really focusing on painting, or um and I had been doing youth work for year and years and years and I love that. I, yeah. Interesting relationship to mortality.

Ethan: So, um, why did you leave New York? What brought you back to Maine?

Tom: Um, I mean a couple of things. One was, I was mugged, about a year before I um, left. And that was pretty traumatic. For me. So I felt, you know for the most part of my time in New York I felt safe, you know, and had enough, sort of common sense, you know where you go and what times. One night I locked myself out of my apartment and then, you know, couldn't get ahold of my friend that I was subletting from, till like three in the morning, I cut through an area that I shouldn't have cut through. Um, and, so that, that rattled me, um, trying to navigate working part time, I was teaching um, with, all the medical stuff I was dealing with, some was uptown, some was in the village, some was on the east side, so there was a lot of traveling around for blood work, um, support groups, physician, um, juggling with the pharmacy stuff, so I think it was just more the um, the pace of life, um, was getting to me. Um, and then um, over Christmas break, and I was thinking about not returning to teaching. My mother had a stroke so I, so I offered that to the school as my reason for not coming back and then I didn't tell my mother I had AIDS. I had told my mother, well I was one of the newer ones, and they were cutting back on staff so... I wanted to come back here and regroup, made sense, you know, um, and again, mothers always have ways of suspecting. So I really, I mean, I moved back to Maine thinking I was just going to live out the last few years with having um, a more relaxed pace. I was also asked to help found the People with AIDS Coalition in Maine. and um, I said well oh that carries some of the work, so, that I was doing in New York up to here but um, that was one of the biggest reasons really..tired of standing in line at the banks, and crowds in supermarkets and the subways and .. I mean really there are a lot of things I still miss about New York and uh, and I, I still love going back. And If I could afford to I probably would move back there, but I don't think... I don't know how I afforded it then. Um, uh, but um yeah I really didn't expect. In 1988 I moved back, couple of years that'd be it.

Ethan: It must have been hard leaving school behind.

Tom: It was hard leaving the teaching behind, um, giving up the graduate school I think was the right thing for me to do, I just I actually found out my AIDS diagnosis was just starting at college in New York and there was, I couldn't have done graduate work and teach part time and do all the um other stuff, so um, but I really, really did love the teaching. Um, and what I think was one of the more painful things was, um I dunno five or six years later um, I thought well I you know, the people who are coachers at the humanities department um, could I teach when they're you know evening classes or a couple of evening classes and the pay was well enough that you know, if I took the bus down and back and stayed with a friend and worked I could actually, you know, do it from Maine. um and so when I popped into the office, the uh department coacher didn't remember me. Lots of people coming through, and just, as many years of my life, I did like the seven years Bachelors program and then did teaching for many of those years worked in the humanities departments for work study and then um as a

1 Interview Part. 2

Kailyn Braley and Ethan Masselli

Tom: Um, not too long ago. But I've done you know painting here and there, that um and then go back to photography, and then painting here and there and I think very gradually um trusted that um it didn't seem imminent through the uh HIV AIDs. So I mean, its hard for me right now to figure out the dates, it was just more of a gradual, um, I think, you know, its you know, in a similar vain, he is the same physician since I moved back to Maine and I think at the time there were only three physicians treating people with HIV AIDs and um, and I'm very fortunate for you know, having a very good report with the physician I had, and when I had to start dealing with you know, regular aging stuff, I'm like hmm didn't think it would come to this! You know, Oh, boy! Colonoscopy! (Laughing). Yes, so, HIV is fine Tom! Look at your cholesterol! So, um, and um, and it, I think in some ways, um, I remember I think before the uh, the triple combinations and the um combining the protease inhibitors they um, balancing now, reverse transcriptase inhibitors. I thought, you know, I had been doing so much work to get ready to die if there were suddenly a cure I wouldn't know what to do with myself. I and I think that happened in a, in a much slower way because I was doing all sorts of emotional, spiritual, and practical work you know, making sure my wills were in order, my medical attorney, and then um, I kept on living, and you know, at one point, um as part of that, early on I went on disability. again thinking that I'd probably have a year in half to two years that's what most people had with my particular set of conditions and my p cell count, and um, so, I found myself in a catch twenty two position as I you know, started feeling better once the protease inhibitors started working for me. If I went back to work, I would lose benefits, um, and there have been times when I worked part time but for whatever I report, you know if, four dollars, three dollars gets taken away, and um, and the benefits um, for awhile I was working at the Portland Public Library shelving books. Its just...I love libraries. I love books. Um, and its a minimum wage job and I have to make sure that I'm not making under or over, can't make more than a certain amount, but yah, I figured out once, you know, I was, from what got taken away from my benefits by my reporting that I made, I was making like three dollars and fifty cents an hour, I said well you know I might as well volunteer. And and I did for a while, work helping a man with MS and that paid better but I was um, really didn't get me ahead much financially, um cause of what I would lose. I had to be really careful putting in extra hours in less I go over a certain amount and put my social security and disability at risk. So um... so you know, at a certain point, um, a job offer came up in Pendle Hill, which is a Quaker, study center outside Philadelphia and the woman who taught the art program part of that was retiring and she started created this wonderful art room with twenty four hour access and kilns and um, looms, and you know frames, you know, I just... my sacred space. And, um, and I thought well what am I going to put on my resume? You know, I had started, actually started teaching at school of visual arts um even before I got my, starting to work on my Masters, to stepped into, start teaching first by substituting and then filling in for some instructors on sabbatical, understanding that I'd work towards my Masters. Then I really loved teaching. Uh, here's a, once I decided I'd needed to go on disability and move from New York I sort of left that behind. You know, all these years of no work, um, .. I think once I put together all of my volunteer work that I had done, I'd hire me. Um, and and you know really, what was I think tremendously helpful for me to see what I had been doing even though I wasn't getting paid for it, and if I find that I did not get the job and at least I was one of the finalists I think.

The Arts

HIV/AIDS

Health, Aging

Life Struggle, Internal Struggle

Quaker

The Arts

Education, Masters

Disability, Volunteering

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Kailyn Braley and Ethan Masselli

Interviews, I felt good about that. Um I think that started my long story of, you know, very unusual relationship with Martel and with having spent a lot of time, you know, preparing to die, and then what do you do when you keep on living and you know, what's my retirement fund? Yeah, uh, hope my partner remembers me in their will (laughs). Um, You know, no retirement fund, no investments, no, its um... so I think um, this last September turned sixty and so a major milestone for me, thinking I outlived AIDS, and I outlived, you know, two bouts of cancer related to AIDS, I outlived depression which I think is still something that could take me. Um, I've had a lot of falling strings with some dark depression including suicidal ideology, ideations, um, I but you know I'm thinking about old age, so you know maybe I started, you know, been pretty lucky with the HIV, and you know my doctor he says you're amazing Tom, he really means it... um but now, having to make choices of where do I focus my energies and what can I give up to, and um there's a piano keyboard up there and I will never become proficient at it... so (laughs), I um, yah, do I want to spend more time just really focusing on painting, or um and I had been doing youth work for year and years and years and I love that. I, yeah. Interesting relationship to mortality.

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Ethan: It must have been hard leaving school behind.

Tom: It was hard leaving the teaching behind, um, giving up the graduate

Relationship

Finance

HIV/ AIDS

Health

The Arts

Mugging

Health, Treatments

Education, Teaching

HIV/ AIDS

PWAC

Finance

Teaching

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AIDS, Diagnosis

Teaching, Education

Deteriorating Health

Kailyn: How did you get into starting the People with AIDS Coalition in Maine?

PWAC

Tom: Well I was asked to by um, another person living with AIDS here in Maine, and um , I forget how we met, or were introduced. Oh, I think I had come up to um, during winter break, at um this AIDS summit that I had attended and I remember Dale McCormick being there, Peaches Bass, Perry Sutherland, and um, a few other people I just you know, Diane Helsey, were just these amazing people of the forefront of AIDS activism in Maine and I think that there was one other person living with AIDS who said I think we really need a People with AIDS Coalition here, would you be willing to help found one? It was, it was hard, um, because the concept is based on self empowerment so people asked, so what is it going to be? And I said well really whatever you need or what you want it to be. And they'd say, so what is it going to be? So eventually I said well the one in New York has a drop-in center, has you know, these services, I think a drop-in center is vital and might have maybe a food bank..uh, attached to it. So I think once they got , you know, a sort of a grasp on this concept , uh, of what it might look like physically, and then people were able to get behind it. I think um, it, flourished for a while and then I think it was hard when actually some money started coming in and, and then it became some confiding of how to use it or not to use it, and then um I eventually, I resigned. A woman who um, started, Terry, who was, they were very public about living with AIDS and having their daughter attend school at a young age, and a lot of fuss about it and she decided to move to Florida with her husband, who had been an Iv drug user and they recently married, he was also HIV positive, so it was not working out well for them and they needed to come back, and some private medical thing come back, and asked for I think five hundred dollars being donated towards that cause and I thought, the um, board agreed and authorized it and then the board members said well but you know, husbands a drug dealer, sorry not a drug dealer, a drug user, we can't trust him. He's not the one asking for the money. So they tried to block it, um, tickled some of the people of the state about the ethics, and wrote the

HIV/AIDS, Activism

PWAC

HIV/AIDS

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Kailyn Braley and Ethan Masselli
check out anyway and then resigned from the board.

PWAC, Resignation

Ethan: And you also worked with the AIDS Project as well.

AIDS Project

Tom: Yeah, yeah. That was um, I wasn't there for that long after, I think once the People with AIDS Coalition started getting off the ground I felt that could be a potential conflict of interest but um, um, again, found that a very sort of amazing time, especially in the early years with the AIDS project. And some amazing people stepping forward.

PWAC
AIDS Project

Kailyn: How has the stigma of HIV changed over the years, do you feel like?

HIV/AIDS, Stigma

Tom: Um, Certainly think its less, um, a flip side into that, I think because people aren't seeing the devastation that can still happen. There is a rise, in infections particularly among young gay men I think there are those who are much more cavalier, and become infected. Still at the same time, for a number of years I thought, let me try some online dating sites and, and I think the ugh, all the coding for the "healthy drug free" is basically "Don't be HIV positive". um, So I think, yeah, theres still a lot of that out there. I kind of gave up on dating after many years of, um, i was actually really really okay with being single but for some time, yah know, some times that romantic spark would, you know, start to appear and my ethic was to let people know I was HIV positive before it progressed so I knew ahead of time. How to react and, I suspect, you know, cant be sure a hundred percent of the time, but a lot of them were like oh lets just be friends for now which I think, I got a lot of friends. Too many, friends and I, I cant keep up with them all and you know, um, so um, You know, it has changed and its still out there. I think the stigma is still , still very much out there. My choice to sort of remove myself from, from dating was I think, Part of I was tired of facing, and also I think I was just feeling kind of ok with being on my own. Um, without my mom, I wish I had someone, and sort of got fixed up with the person I'm with now and the lesbian Quaker Unitarian gimbal, heres this nice gay man, heres this other nice gay men , you should meet. And uh, and here we are, six years later, but I really, uh, hadn't expected to be with anyone again.

Health

Dating, Romance

HIV/AIDS

Stigma

Quaker

Ethan: Yeah, I was just gonna say um, whats it like being with someone now, after not dating for so long? Like you said you didn't think that it would happen but...

Dating

Tom: Yeah, it was, well at first I think it occurred very very slowly and cautiously and that might have been partly too our ages and our um, I, I had a friend who lived next door and I had known her since high school. I said you know, there, no initial spark, you know, no fireworks, you know no hormones raging. She goes, Tom, you remember some of those relationships we got into where the hormones were raging and the fireworks were going? Remember actually I married one of them, remember how that turned out? And I go, oh yah! Uh, (Laughs). You know, theres something nice to be said for slow, and easy and uh, and I also told this story to other friends, they said, and theres something to be said for the fireworks too! I said yes, that is true as well. Um, I think there was something about just the

Aging, Dating

Kailyn Braley and Ethan Masselli

ordinariness of being with one another and just the day to day stuff and you know, hadn't moved out of here to Hallowell and walking Zoe around back cove, and just complaining about people not listening, and my dog going this way and that way and I thought, I like this, again, just the ordinariness of it. The other I think I mentioned he had been married to a woman before and has three adult children and now two grandchildren so, I want to step in to... his eldest son is still, has some challenges with his dad being gay. Has been nothing but gracious to me um, but his you know, his divorce happened, you know, I think when they were kids during high school and it was a traumatic time for them. Still, um, work very hard with his ex wife to co-parent, you know, and he's still very good friends with his ex wife and Im very fond of her too, but that I think thats something I never think I might've... dated someone once who recently come out with a seven and eleven year old boy, you know, it never went anywhere but, it you know grabs my hand cause thats what dads do when they walk down. I think I like this! And you know, being the, the extra grandparent who doesn't really have to discipline the grandchildren you know I love being around the grandchildren. Thats great fun. It is, its nice to have the um, the company, the um, and to be honest I think its kind of an income so theres um financial stability that I haven't had in a long time. Grateful for that. Um, chose he's not wanted to get married, you know, I brought it up and our concerns with you know, goes before me , my social security is like this, is pretty much. My partner says he's, he's not ready to get married again and I think when he first said that I thought he meant to a woman again I didn't, but you know we met before the um federal changes, happened and I think, you know, it didn't matter to me that much until it changed federally and then I um, It might not be the most romantic of things but I thought um, financial protections that I would have when we married, something I would not have had before. Still need to, place some legal ground work.

Relationship, Dating

Finance, Stability

Ethan: That kind of moves us into our next question that kind of came up last minute, but we were wanting to see what you think the implications would be after the election that we just went through?

Election

Tom: Since, I couldn't imagine the election happening, I couldn't imagine LePage, getting elected Im not sure IM good at predicting anything. Right now, I think what my hopes are, um, what really kind of took me by surprise is was the you know, the sort of shock and despair that I Did feel ,a and I mentioned Im prone to depression, um, I was on my phone, I think the next day, with someone of a camp, committee for a friends camp, its a Quaker camp, and I , you know , we are doing work to help you, embrace values that, you know, empower women, that are, you know, inclusive, um, you know we're continuing to learn about gender fluidity and um moving forward with that, and I thinking this is what I get to be a part of and this is um, the sort of, made me feel like I need to recommit myself to these, you know, it may seem like, you know small things, but I think if they were to change lives of others and help others, and you know, protect the other people find ways to hold to their own truths and values um, and then there, theres something, then theres some hope. So, I think again, its my hope is that instead of becoming, you know, more divisive, I think theres going to be some tough times ahead quite honestly. I think theres going to be some really painful things that are going to happen and my hope is that we move from a place of love and compassion and strength and what is best about

Internal/ Health Struggles

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Kailyn Braley and Ethan Masselli

us, instead of moving into that, that confrontational place. And the second thing that I did that um surprised me is that there are a few people I know who are just very heavily infested in the campaign for Hilary, so um, I sent them each a note saying, you know, just giving them some extra love in this hard time, and each of them how much they appreciated it cause they were devastated and, I um, yeah. Its yeah, its scary and I think that it kind of surprised me that, maybe its some sort of self defense mechanism of what can I do positive so that I don't sink into despair, cause its so easy to go to. Someplace that Im familiar with. Im hoping that , the anger and the disappointment, you know, gets channeled in positive ways.

Election

Internal/ Mental Health

Ethan: You've been through a lot too, and you've made it through a lot of hard times over the years. What would be your words of advice being for times like these?

Tom: Just saw the um film last night, Dying to know about Timothy Leary and Ram Dass and um, Ram Dass took the name, was given the name, which means servant to god, and I think you know he's., was that what it was? Was hoping for something much more resolved. But I think for having such an unconventional nonwhite, male, typical kind of life, queer, that having a life of service in whatever ways, you know, being, I said I worked a lot with youth, um, I think giving, service is. The greatest gift. Sometimes when Ive been in some of my hardest depressions and often went on weekend retreats with these teenagers I have to be present to them, with whatever going on in my own life, you know, put it in the background and absolutely be there for them and thats so ironically tremendously healing for me. I think that the more you can give service in the ways that were best used, some kinds of... Being in staff meetings after our youth retreats and thinking, Tom, felt well used in the best sense of way, and you know, how I bring my gifts to service might be very different than having someone else bring their gifts to service. there are those who are, you know, much more gifted in, their activism they're much more those who are very gifted in the political relm, there are, and those who are gifted in arts and writing. I think you know, find that place where you're able to give yourself and ... manifest itself.

Queer

Activism

The Arts

Kailyn: Was there anything else that you wanted to talk about before we finish up?

Tom: Oh, probably. Im sure ill think of you know, a half dozen things as you're driving down the road. Um.

Ethan: I was going to say, before we wrap it up, is there anything around your art that you wanted to speak of? We didn't really get to touch on what you do...

Tom: Um, in Quaker traditions there is something called a clearness committee, which a little side story... When I was having a different clearness committee, when its usually when someone is taking a membership or wants to get married, has a significant event in their life which they need some help with and its really more about them asking questions to pull the truth out of you. So my sister took the message once and she said, Tom, someone called about your queerness committee. (Laughs). She was trying to be so sweet about it, its true you have to be re-

Quaker

Clearness Committee

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Kailyn Braley and Ethan Masselli

certified every so often (Laughs). So its kind of a joke we call it the queerness committee, but my clearness committee. And I call together a sort of unofficial one as I turn sixty and part of it was around my artwork and one of the, people in the group is another gay man, who is also after his retirement, become an artist. And I think there is still a lot I hold back of um, how much I reveal of myself and my own sexuality through my, through my artwork. And uh, the portraits I do, I've done, they tend to be mostly of young men, I mean theres, I use the um, youth that I work with, the Quakers, um, and so one thing I do but, um young men first, and then I started getting afraid of what thats gonna look like when Im you know, chasing around these um, young men, as this older gay man, you know don't want that creepy thing to come in. Um, and that I do work with youth, so even when I was photographing nudes just to really hold to myself kind of what I wanted to be, impeccable standard of professionalism. That it was not to be exploited, cause Ive known some other photographers who were not so, and they are asking people to model for them but I wanted to be really very clear about establishing and holding that reputation, but I think part of it within there is there is a certain amount of internalized homophobia that I censored myself. I hold my work back and the eroticism, um, some of the you know, nudists Ive done, Im also working for photographs, of again for people who are photographed often the paintings I chose are....I don't know if Im shy or I still feel awkward about how much of my sexuality comes out through my artwork.

Clearness Committee

Aging, The Arts

Sexuality, Quakers

The Arts

Internal Struggle

Kailyn: What was your experience like first, I guess, shooting, a naked man?

Tom: At the time it was film photography so um I often expected that I would go through at least two rolls of film and Id get nothing out of... and I did that a little bit purposefully to put the person in front of me at ease. And I realize it also put me at ease. And It was um, so very individual, I mean there were some people who were actually comfortable, um, and I hardly had to give any direction, others you had to, now, what, now what, now what, um, and um, so I, I think very individual, um, I think one of the better compliments I ever got was a photographer Herbertz had an exhibit in Boston many years ago and I was showing my work, um gay mens gathering in Portsmouth, New Hampshire, and someone you know, I like yours better Tom because its much more personal. I realized thats probably because I have some sort of relationship or at least know a little bit about who I'm photographing. Professional models, um, you know once or twice I think I've photographed someone who's done so modeling for Maine College of Art. And he was also doing poses really for drawing a painting. And I was not very good, still not very good as a director. I still find it mysterious. So I think when there is some sort of relationship with that person it makes a big difference. But it is um, I mean when Im, when Im photographing someone Im really in professional mode Im, my mind is about aligning, composition, um, you know how are things framed. Yes, there, there is some omnipotent voyeurism to it but its uh, I think that goes sort of in the background to um, hoping to create and capture something, and also, again, I'm just very protective of that professional relationship. You know, I don't want to embarrass anyone, I don't want to embarrass myself you know Ive had um, you know, some unexpected things have happened, and you know, sort of, sort of things in my pocket. So if hard on's happen do I continue photographing or should I stop, you know and, and

The Arts

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Kailyn Braley and Ethan Masselli

some people were fine with it, others. Yeah, just wait a moment. But, sometimes I would think I was probably more nervous than the model.

Ethan: Well, as we wrap up, Tom, is there anything else?

Tom: Ugh, uh yeah, I'm sure, sure that there is. Um, I think you know, one thing we didn't touch on um, I think aging as a gay man is, is something that's more and more of us are facing and figuring out how to deal with and cope with. I think when I um, first started feeling, sort of, the stings of ageism, you know, I was turning forty, and you know, getting you know, still go to the clubs every once in awhile. You know, um, you know, very clear where I seem to belong, where I didn't seem to belong and um, that was um, I think that's uh, I think, I can't remember the last time I went to a gay club. And you know, the online dating things for anyone over a certain age it seemed like next to impossible to you know get a response. But you know, aside from that, um, there there also talked about some potential and intentional living communities and what happens when we have to go into nursing homes, are they gay friendly? So there's a whole lot of us who were able to come out and now are, now are aging.

Aging

Bars, Clubs

Dating

Community

Ethan: I'm going to turn it off now, okay?

Tom: Yup.