

***About Health TV with Jeanne Blake***  
**Preventing Substance Abuse: One Family at a Time**  
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JEANNE BLAKE: Welcome to *About Health TV*. I'm Jeanne Blake. Millions of American youth use illegal drugs and far too many die from overdose. Twenty-one year old Peter Bildner died from an overdose of heroin a little over a year ago. Jim Bildner joins us on *About Health TV* to tell us what his family is doing to save other young people from substance abuse. Jim, thanks so much for coming in.

JIM BILDNER: My pleasure.

JEANNE BLAKE: I know that this is not an easy conversation for you to have but you've been very brave about being open with what happened in your family and what happened to Peter. Why have you made that choice to be so open about it?

JIM BILDNER: Really because the whole question of adolescent substance abuse and actually even more particular, the impact on families, as we went through it and as we spent the last eighteen months really trying to figure out what's out there for families and what their experiences are like, it became very clear to us that our experiences are the same as thousands of families going through the same thing and Peter's death is a matter of history and there is not much, there is not anything we can actually do, but we can try to help those that are going through this process now and then this initiative is our, is our attempt to really do that in a meaningful way.

JEANNE BLAKE: And this initiative is part of the Massachusetts General Hospital Center for Addiction and Medicine. So tell us a little bit about what you and your family are doing.

JIM BILDNER: Right. So let's first focus on what the issues are. We sort of have two very difficult issues: One: substance abuse, particularly around adolescents and that's where Nancy and I are focused because adolescents in this country are the greatest risk and we hope that we can make some serious progress there. The other

issue is that once an adolescent is addicted, the treatment protocols that are available vary in every conceivable way you can think of from quality as you know, the treatment centers themselves conflict each other as to what the best practices are, and in fact, there are no best practices.

JEANNE BLAKE:                   And that's the case for adult treatment as well as for young people.

JIM BILDNER:                   I'm sure it is. And in our experience, families are just left alone as they sort of navigate through this. It's compounded by insurance or lack of really meaningful contributions from the insurance industry to help families go through this so what that leaves them is with theoretically a healthcare system that's designed to treat medical problems but when it comes to substance abuse, it leaves these families alone and that is the primary effort that we are trying to create at Mass General through this program.

JEANNE BLAKE:                   And let's talk about the elements that, that are included in that.

JIM BILDNER:                   Well, the first and foremost is, so take a typical family going through this. The onset, as in our case, is usually sudden and it's not because the substance abuse all of a sudden came out of nowhere, but because there is so much denial on both the family's part to not want to believe it can occur, and that happens again regardless of economic circumstances as I've said many times.

JEANNE BLAKE:                   Absolutely.

JIM BILDNER:                   Substance abuse is an equal opportunity killer. But all families, rich, poor, whatever, defer the day of their own reckoning with this as long as possible because no one wants to believe that their son or daughter is an addict. But when that onset occurs, unfortunately it occurs, usually at night, usually on a weekend, and there you are. You suddenly realize, holy smokes I've got this unbelievable problem and you begin to figure out, okay, where can I get help. And an emergency room is not a

solution. Often you're confronted with you might be able to reach Faulkner or Mass General or whatever hospital is closest to you but no one takes admissions during the weekend. If you try to navigate through insurance, it's impossible to get clarity there so, the most important thing we think we can do initially is to have at least a center that's staffed 24/7 that is familiar with these issues so that a family in crisis has a place to call that will be staffed by a clinical social worker who will know these programs and, depending on the person's location, can actually go see somebody immediately or be referred to somebody who can see them.

JEANNE BLAKE: I want to just take one step back and ask you to talk with us about when you learned that Peter had a problem with substance abuse.

JIM BILDNER: I mean, again, as you probably know from the Globe article, I mean, in our case, it really was as it is mostly with adolescents it's a fairly long unfortunate curve and so for us the moment we really realized that Peter was addicted is when one day I went in and basically took his book bag and flipped it upside down and found heroin and tourniquets and syringes and undeniable evidence that Peter was addicted to heroin and that was sort of our moment of awakening.

JEANNE BLAKE: And that was how many years before he died?

JIM BILDNER: Oh God, that was a good two and a half years, almost three years before he died.

JEANNE BLAKE: And when you talk about a family's denial which is part of the disease, what, how did that work for you and Nancy, I mean, did you say there's a problem here and you assigned it to other things or did you truly not see it.

JIM BILDNER: Um, well you have to go, I mean, from that, so it was almost three years from that moment to Peter's death, but it was at least three years from that moment when, and one of the problems with this disorder particularly, is the fact that it is often misdiagnosed and one of the issues that we faced and many parents face is that behaviors that they can't explain and then they'd be identified at the school usually fairly

obliquely which doesn't help the families and that's another subject we could talk endlessly about. We'll go to a primary care physician and the primary care physicians themselves are not skilled to recognize what is adolescent behavior and what is the early signs of substance abuse that can kill these kids. And even if they are aware of it, they have nowhere to go with it so often GP's and primary care physicians who are the first really to be able to identify it choose not to because they really don't know what to do about it.

JEANNE BLAKE: Exactly, and if they do know what to do, they know that the system can't sustain as many people as need help anyway.

JIM BILDNER: And the disease is stigmatized. So no one wants to be told, hey, you know your son's a full-blown addict, so there's all, forget the enabling, and the denial that takes place both at the family level and the other thing is addicts typically are very smart.

JEANNE BLAKE: Exactly, very manipulative, will hide it well.

JIM BILDNER: Right, right, so you have that going on at a family level, and then at a health level, you have primary care physicians who don't want to be able, who can't recognize it, and if they can recognize are reticent to identify it and then don't know what to do with it and you have a recipe for disaster.

JEANNE BLAKE: So you are taking one big bold step in creating a national model that will hopefully then be used in other

JIM BILDNER: Right.

JEANNE BLAKE: Communities and cities across the country? When you did discover that Peter was using heroin, what did you do? What were the first steps that you took as a family that took you into that maze that has lead you to want to help other families walk through it?

JIM BILDNER: I think we, the first place we reached out to was McLean, because McLean does have both an in and an outpatient program for adolescents and for adults. And again to what I said earlier, I think we, I can't remember specifically the date but I think it was a Friday and they couldn't take Peter until Monday because it actually was Memorial Day weekend so we did what every parent has to do which is essentially keep your kid under house arrest to be able to make sure that you can at least can keep them sober but heroin as you know and other drugs have incredible withdrawal symptoms. So it was a very difficult four-day period. We did get him into that outpatient, actually inpatient program for a few days and then he went to an outpatient program.

JEANNE BLAKE: Like over the weekend? I mean did he go through withdrawal at home?

JIM BILDNER: I'm trying to remember. I can't recall specifically what took place that weekend but it was a nightmare but it was one of countless nightmares and that process that you go through with kids is a continual nightmare even for the ones who can recover because the other reality that's difficult for the adolescents and very difficult for the families is this is a forever problem.

JEANNE BLAKE: Right.

JIM BILDNER: As I've told you before the show, this weekend at a Mass General symposium where Marty Kane, one of the clinicians spoke and really was informing the audience because somebody said, are there cures for this? To which he responded, "There is no cure for this." Even if you can get successful sobriety for years, this a day-to-day process and as hard as that is for parents to understand, it's impossible for a 16-year-old to understand that however they got themselves into this problem, it's a life-long disease now.

JEANNE BLAKE: A 16-year-old brain isn't wired to be able to consider a consequence or consider a future.

JIM BILDNER: Right, right.

JEANNE BLAKE: And so for them to understand that, thus recovery is so challenging. Relapse is so common and I think people don't understand that, that how common relapse is when someone tries to begin recovery from substance abuse.

JIM BILDNER: And therein lies the other problem, which is even in our experience, Peter was in seven treatment facilities, and that's, by the way, that's sort of the common number for like kids of Peter's age and it doesn't actually have to be heroin, it generally someone who reaches that point of addiction will go through seven, eight, nine treatment centers before they really have a shot at recovery. Now, the real problem is that the treatment centers, and we've been through them all, not them all but we've been through those that are perceived as the highest quality and even those that are not perceived as having such high quality but all of them generally throw these kids out when they relapse. And you have to ask yourself, how can you be a treatment center for substance abuse addiction when every expert knows relapse is virtually 100%.

JEANNE BLAKE: Exactly.

JIM BILDNER: And multiple relapses. And so what happens is these kids end up traveling across the country as they get thrown out of another one and put into another one and thrown out, and there's no continuum of case management which is another key component of what we're trying to build here.

JEANNE BLAKE: It's interesting, I want to go back to that, because that to me is fascinating and a really holistic approach, is what you are describing in the program that you and Nancy are helping to create.

JIM BILDNER: Right.

JEANNE BLAKE: But it's, I just had this flash that in this country we're trying so hard, I come from a family of a lot of substance abuse and alcoholism and it's, it's hard for me to imagine that somebody asked that question, is there a cure? Are we really still at that place?

JIM BILDNER: We are.

JEANNE BLAKE: Wow, that's shocking for me.

JIM BILDNER: Because it wasn't just one, I mean, all

JEANNE BLAKE: Really?

JIM BILDNER: Yes, right.

JEANNE BLAKE: So if we are still at a place where we are explaining to people, look it, addiction is like cancer, it's an illness, and then you take a kid who is in recovery trying to get clean, trying to stay alive and they're in treatment and they relapse and they throw them out, if your cancer came back, they wouldn't throw you out of the hospital.

JIM BILDNER: Right, right, and that's, that's I mean aside from the lunacy of the medical protocol, because they throw them out with passion, and instantly by the way, for self-institutional reasons because they don't have the resources, they don't have the capability, because they want to demonstrate that, you know, it's a zero tolerance, which are all the right things but a treatment center to be really effective to have any chance of success, has to have programs that have primary care, have relapse care, and then can have graduation and not graduation as in a high school graduation, but graduating care down, and then the thing that's uniformly lacking across this country is that once these kids go back into communities whether they go back into their home, they're back on their own again, and they have no intrinsic self-support to be able to do that and you know, what Nancy and I feel so strongly about doesn't exist today which is they need life coaches.

JEANNE BLAKE: Right, right.

JIM BILDNER: Literally if you wanted, I mean, if you wanted to come up with a protocol that had a good shot of success, kids would have to go through treatment

facilities, relapse recovery and this sort of step down approach but when they go back into their environment, particularly a college environment, they need to have somebody who is going to hold them accountable and be present in their lives on a daily basis and that just doesn't occur and that's why success is so limited at the moment.

JEANNE BLAKE: So the second component that you talked about was really, the managing the recovery which you just obviously touched on. Tell us a little bit more about what that will, what that will, did I skip a step? When someone, someone will have a place to call 24/7 and there will be someone there that's knowledgeable, that is, that can identify potential programs that can say, okay, we're going to help you.

JIM BILDNER: Right.

JEANNE BLAKE: And then the second step is?

JIM BILDNER: Well, there's, so let's just look at all of the possibilities here. So number one, we want to have a place that can respond on an urgent basis immediately. And essentially triage the problem, you know, what is their moment of discovery? What's the current state of the adolescent? Where does the family live? So fairly basic information to be able to figure out okay, come on in, you're within a radius that we can deal with or you need to go over here but they are an affiliate of ours, or are a partner with us, so we have identified areas that at least we believe at the outset, meet a standard of care that's acceptable to the Center. Beyond that, for those that we can treat, and for those that are affiliated with this Center, we want to be able to have long-term case management and then the fourth component, which is even more important and doesn't occur anywhere, is outcome data. You cannot get any reliable outcome data for any treatment centers in this country today. And it's because they don't want the data and as a requirement for anybody participating within our services at MGH, we are requiring people to consent to having long-term outcome data because without knowing which one of these variables works, we can't replicate it.

JEANNE BLAKE: So you, you are really working in partnership with Mass General to change the whole paradigm of treatment for addiction?

JIM BILDNER: Right, and the beauty of Mass General is they are research-based. And that outcome data you know, is so important to our understanding in addiction and substance abuse again, as you know, well, let's just look for a second holistically, so we could, if we could stop drugs from coming into the country we could solve this problem, but that's for another life. Within the substance abuse itself, there is a lot of science going on at the brain chemistry level.

JEANNE BLAKE: Right.

JIM BILDNER: Right now there is a lot of work in sub primates. Hopefully that might long-term be able to help us identify those greatest at risk and ultimately maybe be enabled to do long-term blocking to prevent use but the outcome data is so important in figuring out within the context of behavioral things what works, what doesn't work and again our ability over a 30-year period of time to be able to identify. Here's one kid, here's another kid, here's another kid. These are the places they've been and the treatments they received and here's the outcome will help us ultimately figure out what our best practice is.

JEANNE BLAKE: Exactly, and those will be hopefully replicated nationally.

JIM BILDNER: Right.

JEANNE BLAKE: Let's step back in to what I think was three. The case management. Once a young person goes or young adult goes through a treatment program and is dumped back into the community. What does that really look like under your program? What does that actually look like to both the person who is addicted and the family?

JIM BILDNER: Excuse me, I think, the, well first of all, it's a work in progress. I mean the most important thing is.

JEANNE BLAKE: Well, I think it will be. Don't you? I mean any new thing is?

JIM BILDNER: Yes, right. From a conceptual standpoint, the most important thing is continuous contact, so at its most basic level, there is accountability, you know, whether desired or not from the adolescent's standpoint and from the family's standpoint and from the Center's standpoint, it's basically in existence that there be regular contact as well as therapy. Now the difficulty is that kids do leave the geographic, you know area that they are in and so what's very important is that as we begin to move these pilots out that we have case management models in different cities that will be able to address this. And that's our ultimate hope is by understanding what works and beginning to see some evidence that it does work we'll be able to replicate this in cities around the country so that we're not going to be able to have the case manager throughout the country instantly but we will be able to seed pockets that can then develop themselves.

JEANNE BLAKE: When you say continuous contact, I know it means one or two phone calls a week right?

JIM BILDNER: No, I'm talking about much more frequent. I mean, one or two phone calls a week is no contact to me. For an adolescent, regular contact is one or two or three or four or five calls a day.

JEANNE BLAKE: From Mass General to the person?

JIM BILDNER: Right.

JEANNE BLAKE: And that's why you're limiting it to 50 people?

JIM BILDNER: Right.

JEANNE BLAKE: For the beginning stages?

JIM BILDNER: Right no, contact is,

JEANNE BLAKE: Wow!

JIM BILDNER: Should be expressed hourly not

JEANNE BLAKE: And is this to the person who is going through recovery?

JIM BILDNER: Yes.

JEANNE BLAKE: And what about, what about to the family?

JIM BILDNER: Well the family, that's another one of that other discoveries here is that clinician's historically only focus in on the adolescent or the patient.

JEANNE BLAKE: When we know it's a family disease.

JIM BILDNER: Right, so the families are left sort of on the outside looking in and so our hope is that through a parent network, they'll be able to have regular contact with folks like us and other parents who've gone through it or are going through it.

JEANNE BLAKE: Ah, okay, then that is incredibly important. When you bring up, when the person, the case worker is in touch with the person who is going through recovery four or five times a day, what is the involvement, I'm trying to picture this, the involvement of the entire family because I'm getting to a place of two questions, one, often the family is not intact, if a child has gone through years of substance abuse there can be, he could be disenfranchised, not living at home. And what is there in the program that tries to bring that family back together and help them get well again?

JIM BILDNER: Yeah, that, I'm not sure in the near term we're going to be able to address that because the, sort of the biggest gap, aside from all the others that we've talked about is the sort of literal hourly contact with the individual. One, you're right. Many of these families are not intact and many of the families that are intact aren't engaged, so you know, that puts you behind the ball to start with.

JEANNE BLAKE: There's a particular problem that I keep hearing about for and Peter was 21 when he died, but when young people turn 18, it is a huge problem for parents there is practically nothing they can do.

JIM BILDNER: Well there's nothing they can insist on doing and,

JEANNE BLAKE: There you go, big distinction.

JIM BILDNER: Yeah, yeah, yeah, and I'm glad you raised that because I think the real pivot point and the point that we can make a difference on, not just through the Center but by speaking out so loudly, is a parent came up to me after this talk last Saturday and they have a 16-year-old and they live in a community around Boston and they acknowledge their child has a substance abuse problem and they're in this behavioral pattern of trying to figure out what the right regimen is and meanwhile, they're running against a clock that they're not even aware of so.

JEANNE BLAKE: That's right.

JIM BILDNER: As they mull over this option or that option or that option, their leverage to actually compel their child to do something diminishes by the hour literally and I think we can help people understand that any recognition at any age prior to 18 is a gift because you do have the right to compel your child to do whatever you believe is right and that is such a benefit that evaporates the day, the hour that child turns 18 and I don't think, I mean, you asked before do people still think there's a cure, people still do not understand what addiction is and what it becomes and what the consequences, forget the legal consequences, how it destroys families and so there's not even a sense of urgency and I can understand it because for us, we were in that same predicament that this family that I'm describing which is trying to think about what the right regimen is plus the folks that you're talking to give you precisely the wrong advise which is keep your kid in school. You know, how will this look on your college record? Forget the college record, you want the kid that's alive.

JEANNE BLAKE: I was talking with a family on a different topic yesterday. They had a son who is experiencing depression and that family was caught in the same mindset not understanding at first that he was living with depression, but keeping completely focused on the fact that he had to stay on track.

JIM BILDNER: Right, forget it.

JEANNE BLAKE: And had to stay in, he was a junior, oh, the junior year is the most important year.

JIM BILDNER: It's not the junior or senior, it's whether your kid will be alive next year. That's the right focus point because anything beyond that is just a godsend and if parents really understood that, they would really get, they would be better served.

JEANNE BLAKE: Well hopefully they will, and they'll gain that message and just an enormous support and access to resources through the program that you and Nancy are helping to found at Mass General and I congratulate you. I know that you have been through a tremendously harrowing time in your life and I applaud you for speaking up.

JIM BILDNER: Well, thanks. I'm glad. Thank you for the forum to do so.

JEANNE BLAKE: Just tremendous courage on your part and you will make a difference and save lives and thank you for talking with us about it.

JIM BILDNER: My pleasure.

JEANNE BLAKE: We'd like to thank you for joining us on *About Health TV*. Actually I wanted you to give the email addresses?

JIM BILDNER: Oh yeah, so for folks that want to learn more about the program: [jrosen@partners.org](mailto:jrosen@partners.org).

JEANNE BLAKE: Okay, good. That's Joy Rosen, she'll be getting a lot of emails.

JIM BILDNER: Yes.

JEANNE BLAKE: So again, we thank you for joining us, I'm Jeanne Blake and I'll see you next time.