

## Parents Are Hard To Raise® S03- Episode 107 Transcript

[00:00:00] The world's becoming a dangerous place for us women. Lipstick bodyguard looks just like an innocent little lipstick but it will instantly drop any attacker to his knees so you can get away unharmed. Lipstick bodyguard fear no evil. Get yours today only at LipstickBodyguard.com.

**Announcer** [00:00:37] People tend to associate arthritis with aging. The truth is people of all ages get arthritis, including children. This week on Parents Are Hard To Raise®, Seth Ginsberg founder of CreakyJoints.org is here to share some great information and resources to make life a little easier for those living with and caring for people with arthritis.

[00:01:01] Join 180 million monthly subscribers who can now listen to Parents Are Hard To Raise® on Spotify.

**Diane Berardi** [00:01:19] Welcome to Parents Are Hard To Raise®, helping families grow older together without losing their minds. I'm elder care expert, Diane Berardi.

[00:01:28] Seth Ginsberg is the president and co-founder of the Global Healthy Living Foundation and creaky joints an online community for millions of arthritis patients and their caregivers around the world, who seek education, support, activism and patient centered research. Seth it is an arthritis patient himself and he has dedicated his career to advocating for the arthritis and chronic disease community. He's also a co principal investigator of the arthritis power research registry. Seth Ginsburg welcome to Parents Are Hard To Raise®.

**Seth Ginsberg** [00:02:04] Howdy.

**Diane Berardi** [00:02:06] How are you doing? I tried not to use my New Jersey accent so much, but I don't think it worked.

**Seth Ginsberg** [00:02:13] It's hardly a problem. I'm talking to you from midtown Manhattan. So, I get it.

**Diane Berardi** [00:02:19] So you're used to it.

[00:02:22] So my first question for you is, so how Creaky Joints get started?

**Seth Ginsberg** [00:02:29] Sure. Yeah. So creaky joints is now in its 20th year, so thinking way back when... I was a first year student actually at Babson College living with arthritis that I had been diagnosed with at the age of 13. I grew up as a teenager living with arthritis.

[00:02:49] My mother has arthritis and at the time my grandmother had arthritis. And when I went away to college I was feeling quite vulnerable but also quite curious where everyone else going through something similar was out in the universe and this is the dawn of the Internet and I was awake in my bunk bed in my dorm room in the middle of the night quite miserable. First year of school. And I got out of bed and I emailed a former internship boss and mentor from high school, Lou Tharp, and in one sentence I said, There's gotta be a way to bring people together in a positive environment where we could share strength and experience. And fortunately Lou wrote back literally the same day as he awoke that morning and said I'd like to become a social entrepreneur. How about we do this together?

**Diane Berardi** [00:03:33] Wow.

**Seth Ginsberg** [00:03:34] And that afternoon creaky joints became a Web site. And like I said, we're now in our 20th year. I'm happy to report I no longer sleep in a bunk bed [laughing] and we're just now doing our bit to as we say, "bring arthritis to its knees"

**Diane Berardi** [00:03:55] And it's true, when we hear the word arthritis, we think it's just a disease of the elderly.

**Seth Ginsberg** [00:04:01] Well right. We think of gnarled hands and joints and ache and our grandparents. And that's partly justified I mean that's the majority of arthritis by population. The older you get the more likely you are to have what's called degenerative arthritis or degenerative joint disease or osteoarthritis... Wear and tear takes its toll. Gravity is a funny thing, you know. It weighs down on us. And eventually those knees and those hips and all of our other joints that we use especially compounded with things like overweightness or obesity and other things that we must do repetitively for example in jobs, anyway takes its toll and that's what causes arthritis. So it's okay to think of it as a grandparent disease but it's more OK and much more important to know that it affects people of all ages. Children.

[00:04:55] Three hundred thousand kids in America alone. And then there's another type of arthritis called rheumatoid arthritis or RA, and related auto immune conditions like psoriatic arthritis that affect a few million people in the U.S. and that affects people in the prime of their lives. Mostly women. A majority of women I should say and that can have an onset in 20s, 30s, 40s or 50s.

**Diane Berardi** [00:05:25] And I was amazed that they were saying about 100 defined types of arthritis.

**Seth Ginsberg** [00:05:32] Oh yeah. Lots and lots of types of arthritis you've you've never heard of and could never spell. But they're very much defined by how they present themselves, what causes them. And I think now most importantly how to address them and how to treat them.

[00:05:49] And I think that's a really important message that I'm going to keep repeating here. And that's these are being better and better treated these types of arthritis than ever before. In fact, dramatically better today than when creaky joints started 20 years ago. And understanding of the biology of these diseases and the biology of their treatments means that we really do have a handle on management of arthritis. It is no longer a sentence to a wheelchair, you know, a lifetime of pain and agony.

[00:06:18] It could a completely fulfilled life, virtually normal. But it's definitely a reminder of the important things that we have to do to stay healthy. Obviously talking to our doctors and things like that, seeking medical care. But I should say, as important or most importantly with respect to arthritis it it's a healthy lifestyle.

[00:06:40] It's eating well. It's exercising and moving and staying positive and losing some weight or not smoking and all the things that contribute to a better outcome, when you have a diagnosis of arthritis no matter the kind.

**Diane Berardi** [00:06:56] You know and a lot of times I find, like with my dad, who has rheumatoid arthritis, and a lot of patients that I see, they say, Oh, my arthritis is bothering me. And so they don't want to move, and they don't want to walk, or do any type of exercise. Where if they do, do some form of exercise or continue to walk and do what they normally do in a ward off maybe the stiffness. They're not going to gain the weight and give them you know a rush of endorphins.

**Seth Ginsberg** [00:07:28] It's a Catch 22. For sure. And you know it's interesting 'cause when we talk with policymakers, regulators you know our folks in Washington and in states around the country, we very respectfully point out the importance of addressing arthritis. Because arthritis is the leading form of disability and immobility. And that immobility is what creates byproduct problems like heart disease, like obesity and hypertension and all the other kind of catastrophic issues that are inevitable when one no longer moves. And if, to your point, arthritis is preventing folks from moving, it speaks to the need to address it, so that they can move and we can get active.

[00:08:18] And so how do you do that, right. How do you scale that mountain right away? And you know a healthy person's analogy is if you haven't worked out in a long time that first visit to the gym is a tough one to finish. And I think for arthritis, you know I think, it has to do first and foremost with teaming up with a doctor, teaming up with a health care professional. I can look at this and appraise it, assess it and understand kind of the bigger picture to chart that path to getting on the right track. And it will involve likely some kinds of medicines. It usually does. But it has to also include other wellness and lifestyle elements that we've been talking about. And that does get you on the path to getting able to being able to move again.

**Diane Berardi** [00:09:11] Now, what special challenges do you see like for elderly parents, living with arthritis?

**Seth Ginsberg** [00:09:18] Well I'd like to speak candidly. Permission?

**Diane Berardi** [00:09:21] Yes. Please.

**Seth Ginsberg** [00:09:23] There is a there is a symptom of growing older that I respectfully have borne witness to and that is called stubbornness.

[00:09:34] Oh really? [laughing] Oh yes. OK.

**Seth Ginsberg** [00:09:39] I'm not pointing any fingers in any directions but I am saying it's a strong correlation. And what I'd like to suggest is you know addressing kind of one's attitude and outlook and mental state and just attitude really toward toward this is I think a massive challenge that we're going to face as we care for the older generations. And helping to change that mindset away from whatever situation it's in that is likely in a more negative direction of course. And by the way, Pain sucks and arthritis is very painful. And there's a lot of reason for people to get cranky and foul moods because of it. And that only compounds the issue and makes it even harder to move up that mountain.

[00:10:37] But addressing the mindset is key early. And something that we think a lot about. You know we like to be a positive. That's kind of our glass half full approach. That's why we're called the Creaky Joints. And we're here to help. We don't want to be a pity party. And creaky joints is enabling folks to not just have this information at their fingertips and like really kind of probe what they can know and then as a result do to feel better or

take care of someone to feel better, but also do it with a little bit of levity, because you know life the short.

**Diane Berardi** [00:11:15] Yeah, you're right.

[00:11:17] Well I try to do everything with levity. You know just... you have to. Otherwise...life has so many challenges, right. Every day.

**Seth Ginsberg** [00:11:28] It sure does.

**Diane Berardi** [00:11:28] So we have to laugh. And that, it is tough, because we know that people with chronic illnesses they have a higher risk for depression. So, I saw on your website you have advice to help patients and their caregivers how to cope with those difficulties that they have and to boost their resilience. Resilience is a big thing.

**Seth Ginsberg** [00:11:51] We're big into resilience. We love resilience. And we do it all kinds of ways and we enable people to to express themselves and we're kind of like you know a modern new age type of support group, if you will. You know and an opportunity for people to come to creaky joints not just access the knowledge or information that we have, which is voluminous, but to take advantage of our kind of regular ongoing almost like a heartbeat of positive and resilient messaged discussion topics and thoughts. A lot of that comes out of Facebook and Twitter, which is like easily the most accessible accessible thing you can think of. And we encourage people to check out the Creaky Joints Facebook and Twitter pages, where like I said, it just doesn't end. It's a nonstop engine of hope and you know we call it "vitamin H" vitamin hope. And give people a little hope. And then the information they need.

**Diane Berardi** [00:12:58] That's great. Vitamin H.

[00:13:02] We're going to continue talking with Seth Ginsburg of Creaky Joints, but if you're a woman, or there's a woman in your life, there's something you absolutely need to know.

[00:13:15] I want to tell you about my friend Katie. Katie is a nurse and she was attacked on her way home from work. She was totally taken by surprise. And although Katie is only 5 feet tall and 106 pounds she was easily able to drop her 6 foot 4, 250-pound attacker to his knees and get away unharmed.

Katie wasn't just lucky that day. She was prepared.

In her pocketbook, a harmless looking lipstick, which really contained a powerful man stopping aerosol propellant.

It's not like it was in our grandmother's day. Today just going to and from work or to the mall can have tragic consequences. The FBI says a violent crime is committed every 15 seconds in the United States. And a forcible rape happens every five minutes. And chances are when something happens, no one will be around to help.

It looks just like a lipstick. So no one will suspect a thing. Which is important since experts say, getting the jump on your attacker is all about the element of surprise.

Inside this innocent looking lipstick is the same powerful stuff used by police and the military to disarm even the most powerful, armed aggressor. In fact, National Park rangers used the very same formula that's inside this little lipstick to stop two-thousand pound vicious grizzly bears dead in their tracks. It's like carrying a personal bodyguard with you in your purse or your pocket.

Darkness brings danger. Murderers and rapists use darkness to their advantage. We all know what it's like to be walking at night and hear footsteps coming at us from behind. Who's there? If it's somebody bad, will you be protected? Your life may depend on it.

My friend Katie's close call needs to be a wake up call for all of us. Myself included. Pick up a Lipstick Bodyguard and keep it with you always.

**Announcer** [00:15:13] You're listening to Parents Are Hard To Raise®. Now. Thanks to you. The number one eldercare talk show on planet Earth. Listen to this and other episodes on demand using the iHeart Radio app. iPhone users can listen on Apple podcasts and Android users on Google podcasts.

[00:15:32] Want a great new way to listen to the show? Have an Amazon Echo or Dot? Just say, Alexa... Play Parents Are Hard To Raise® podcast.

**Alexa** [00:15:44] Getting the latest episode of Parents Are Hard To Raise®. Here it is from my heart radio.

**Announcer** [00:15:49] It's as simple as that.

**Diane Berardi** [00:15:51] You're right Dolly. There are so many really cool new ways to listen to our show. It's hard to keep track. You can join the 180 eighty million listeners on Spotify. You can listen in your car, at the gym, or pretty much anywhere on your smartphone with Apple podcasts and Google podcasts. You can get us on Apple TV, Direct TV, Roku. And like Dolly said, you can even ask Alexa to play the show for you. It's great, because you don't have to be tied to a radio anymore. You can listen when you want, where you want, for as long as you want. And if you're listening to the show one of these new ways, please do me a big favor. Share this new technology, help someone else learn about the show and show them a new way to listen.

[00:16:35] Seth, I was wondering. What resources does the arthritis community most need?

**Seth Ginsberg** [00:16:43] Sure. So they need information that is obviously medically vetted and reviewed by doctors but presented and communicated in very people friendly terms.

**Diane Berardi** [00:16:58] Yeah.

**Seth Ginsberg** [00:16:58] I think there's a large, there's a very large gap between medical knowledge and just human knowledge and consumption. And if you're not a doctor a lot of this is very difficult to understand.

[00:17:10] So we identified this a long time ago and so creaky joints began a series called Patient guidelines that we publish. We take treatment guidelines that physicians follow, which are basically all the evidence based guidelines for how to treat the disease. We

translate it into lay English and then we wrap around all the context and all the other information for living with the disease in the real world, and what else you need to know. They're written and reviewed by patients. They're edited and approved by rheumatologists or doctors. And they're available for free and for download at [CreakyJoints.org/patientguidelines](http://CreakyJoints.org/patientguidelines). And they've become very popular. We have nine editions published now. Of course, a lot of the types of arthritis, RA, osteoarthritis, gout. We have a JIA, juvenile idiopathic arthritis, paediatric and then several others. So we think that's an important resource that obviously we're happy to provide.

**Diane Berardi** [00:18:19] Really important. Yeah.

**Seth Ginsberg** [00:18:21] The other is you know I think as important is the ability for people living with these types of different types of arthritis to communicate how they're doing what their outcomes are, how they're feeling, in ways that are validated and using instruments that are uniform for all medical professionals, as well as for researchers to understand. And to put this a little differently...

[00:18:48] So, a lot of the types of symptoms that come from many types of arthritis are very subjective. What Diane would rank a 6 on a pain scale might be very different than what Seth my rank on that same pain scale for my pain and so forth. Or fatigue for example is another symptom that's very hard to quantify. And what we've been able to do is using the National Institutes of Health, instruments that they have created and validated, we've been able to create an app called "arthritis power" which is loaded with those instruments that basically it's short, short questionnaires that patients can answer, standard questionnaires that they can then bring the results to their doctor to show over time between those visits how you're doing. Because when you go visit a doctor you almost always get asked the question, How are you feeling? Right? Or, How are you doing today? And the answer is almost always how you're doing right then and there. And kind of neglects to mention the last 90 or 180 days since your last visit and that's really important information. And that's what enables a doctor, health care professional to understand how you're doing. And so we call this "patient reported outcomes" PRO's. And arthritis power is a tool that we built with funding from the Patient Centered Outcomes Research Institute which is a government funded body that came out of Obamacare, actually. For the last five years we've been able to build this tool that now over 18000 people are using regularly to share their outcomes with their doctors as well as with researchers, because you can imagine that the research potential and understanding more about people living with these diseases.

[00:20:38] And so those are two examples of resources for patients that we felt were really important and I'm very proud the last few years we've been able to deliver on.

**Diane Berardi** [00:20:47] Definitely. A definite need for both. You know, like my dad has rheumatoid arthritis, I mean his hands, you know are crippled, really. And he gets so frustrated. And the poor guy, and you try to think of, you know like if I make him meals, I have to remember, okay, certain kind of containers that he can open. Just simple things like that, that people don't think about you know.

**Seth Ginsberg** [00:21:16] It's true. And you know a lot of what we do is adapt. But a lot of what we need to do is evolve. And we evolve we're treatments, new medications that are literally today reversing the effects of these conditions.

[00:21:41] You know biologically, that's like enabling the body to make that intervention with its own immune system. Or regrowing cartilage or repairing bone. I mean I just saw a new osteoporosis medicine that literally regrowing your bones. And so you know I think that that's what I mean by "evolve." And then, the adapt is 100 percent right. You know that there are toothbrushes that are just fatter handles and you know what? A toothbrush is kind of hard to use in the morning when you're half asleep as it is. And if you've got hand or dexterity issues. It's two X. So you know I'm sorry to hear of your dad's situation but I hope to share the positive future potential here for him and everyone.

**Diane Berardi** [00:22:32] Yeah. You know on your Web site you have the latest research news, info on clinical trials and...

**Seth Ginsberg** [00:22:39] Yeah. So we've got what we've done is actually a little different regarding clinical trials where we're trying to help people understand what they're all about.

**Diane Berardi** [00:22:50] Okay.

**Seth Ginsberg** [00:22:51] So there's clinicaltrials.gov and that's the opportunity the kind of official clearinghouse for where to go to look for clinical trials. But what we want to do to supplement that or support that is to help people understand what is a clinical trial. What are they about. And then point folks in that direction that they can go from there.

[00:23:10] So but I think it all comes down to the doctor and the patient kind of having that discussion. And I want to be very clear that when you live with arthritis you have to communicate what that means to you and what that prevents you from doing or your loved one from doing. Because when you communicate that to a doctor then they have what's called a "target" to treat too. And this concept called "treat to target" and... Pretty simple. And so what you know you have to do is never assume the doctor knows all about your life, because they don't. And understanding and communicating the challenges that something like arthritis presents, which is either going to be apparent if there's more weight gain or you know more a decline in mood and all that. But also might not be apparent. And I hear doctors all the time say you know the patients who I least suspected to have depression were the most depressed, you know, or vice versa. So...

**Diane Berardi** [00:24:16] You know I know like with my dad, doctors will ask him something and he doesn't say. You know and then he'll say, Well, he really didn't help me.

[00:24:28] You know he didn't ask me about... Or he didn't know about this.

[00:24:32] Well, you didn't tell him. [laughing]

**Seth Ginsberg** [00:24:34] Right. Right. That's why, just a little bit of practical advice. Everyone should always go to the doctor with a loved one and that loved one should not hold back. They should both listen to the conversation but then lean in and contribute with the... "And then" or "as well." And that would be incredibly valuable.

**Diane Berardi** [00:24:58] [laughing] Yeah you're right.

[00:25:00] Now, tell us about the Global Healthy Living Foundation.

**Seth Ginsberg** [00:25:05] Sure. So we are a 501 c 3 non-profit, we're the umbrella organization, nonprofit parent organization for creaky joints. Founded in 2007, technically.

GHLF is funded by grants and contributions and sponsorships from pharmaceutical companies, manufacturers, diagnostic companies, and then research contracts with the government funded Patient Centered Outcomes Research Institute.

[00:25:31] We don't do fundraisers or galas or you know actually we have never asked for a dollar from the public, ever. And we also actually don't sell ads. We have a philosophical opposition to drug ads. We think there are plenty other places to see a drug ad. But this enables us to you know with our corporate partners and then the research contracts that we have to provide all of our services and support and information and everything, Free of charge to the participant. We have a creaky joints Australia. I know you're very popular down under..

**Diane Berardi** [00:26:07] Oh Wow. That's wonderful.

**Seth Ginsberg** [00:26:09] [speaking in an awful facsimile of an Australian accent] So yeah. Gooday. How ya doing. Go on over to [creakyjoints.org.au](http://creakyjoints.org.au). Right on. Righto.

[00:26:19] That was started about four years ago and flourishing. It's really cool. It's its own affiliate of creaky joints just for Australia. And we also have a very popular creaky joints Espanola so it's [creakyjoints.org.es](http://creakyjoints.org.es). And that's en Espanola for the US and Puerto Rico based out of Puerto Rico actually U.S. Hispanic arthritis community.

**Diane Berardi** [00:26:47] That's great. It's fantastic. And how can people reach you, again?

**Seth Ginsberg** [00:26:54] Yeah. So okay the easiest way is through [creakyjoints.org](http://creakyjoints.org), of course. The app is [arthritispower.org](http://arthritispower.org). Creaky joints is on Facebook and Twitter. And you can just search on Facebook or Twitter for that and I really encourage that. And then sign up for our newsletters. We get a free e-mail newsletter once a month. And then if you're so inclined to get involved in advocacy, you can join our 50 state network which is: [50statenetwork.org](http://50statenetwork.org), which is state by state opportunities for People with all chronic diseases to get involved in policy and advocacy at the state level, which is where the majority of the action happens.

[00:27:37] So that's Global Healthy Living Foundation.

**Diane Berardi** [00:27:41] That's Fantastic. This was such great information. I wish we had more time.

**Seth Ginsberg** [00:27:46] In the future.

**Diane Berardi** [00:27:47] Yes. Thank you so much for joining us. And we'd love to have you back.

**Seth Ginsberg** [00:27:52] My pleasure, Diane.

**Diane Berardi** [00:27:54] That would be wonderful.

[00:27:54] Parents Are Hard To Raise® family, I love getting your emails and questions, so please keep sending them. You can reach me at [Diane@parentsarehardtoraise.org](mailto:Diane@parentsarehardtoraise.org) Or just click the green button on our home page.

[00:28:06] Parents Are Hard To Raise® of the CounterThink Media production the music used in this broadcast was managed by Cosmo Music, New York, New York.

[00:28:14] Our New York producer is Joshua Green.

[00:28:17] Our broadcast engineer is Well Gambino.

[00:28:19] And from our London studios, is the melodic voice of our announcer, Miss Dolly D.

[00:28:24] We love our parents, but Parents Are Hard To Raise®. Thank you so much for listening.

[00:28:30] Till next time... May you forget everything you don't want to remember, and remember everything you don't want to forget.

[00:28:36] See you again next week.