

Ballroom

7:57 (2 minutes)	Patient Story   Naomi + Jeff
8:00 - 9:30	Keynote   Bryan Sexton

One remarkable quality about our daughter, Talia, was her openness, her willingness to share her deepest self with others and to create a sense of safety that allowed others to share with her. She was the consummate listener, so present and centered that you knew she could handle whatever you delivered.

Three days before Talia headed to Seattle for a high cervical fusion to treat her Ehlers-Danlos Syndrome, she was the guest lecturer at the University of Oregon, in a class called “The Politics of Women’s Health.” Decked out in the neck collar that she hand painted and looking like Cleopatra; wearing the ACL knee brace that identified her as the athlete she once was, 23 year old Talia spoke about living with a hidden disability and what it’s like to have constant, chronic pain; about being a medical mystery; about being discounted by physicians who cover for their ignorance with arrogance; about the way being an artist helped her face private fears and medical unknowns.

Talia told us later that, after class ended, a student who was a single mom approached her, wanting to find out how she could ensure that her five year old daughter with spina bifida would grow up to be just like Talia: bubbly, secure, fierce, and utterly lacking in bitterness or pretense. Just two weeks later, that mom sought me out at Talia’s funeral to tell me the same thing.

***What if Talia were here herself to share the stories she told that university class, particularly about the harm that comes when doctors who don’t have answers act like the *patient* is the problem, or like the problem is all in the patient’s mind?***

How ironic that our Talia, Listener Extraordinaire, died because those whose job it was to help her, who had the know-how to help her, *failed to listen to her*. With a jaw that had been dislocated during her intubation, a multi-level high neck fusion and difficulty breathing and swallowing, Talia was an airway emergency waiting to happen.

There were not one, not two, but at least **11** discrete interactions in which members of her medical team turned away and Talia’s and our concerns were ignored, dismissed, disregarded— **11** opportunities to save Talia’s life. For 20 hours our pleas to nurses and doctors all fell on closed ears, and we watched in horror as Talia’s airway occluded. Talia herself was aware that her providers had abandoned her. Imagine her abject terror, knowing that those charged with saving her were not going to do so, and indeed, simply...didn’t.

***What if just one of her providers had listened?***