RULES AND DIRECTIVES

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General Comment

I was released home yesterday, June 21st, after completing 7 days in isolation as part of my I131 Radioactive Iodine Therapy for my Papillary Thyroid Cancer. Unfortunately, my release home did not go as smooth as it should have.

I learned from an online support group for Thyroid Cancer that you can request a Geiger Counter reading before you go home to ensure you are at safe levels. Learning this was an option gave me great relief as I am still on maternity leave while going through this. My son is 3 months old and I also have a 2 year old daughter. I wanted a way to be reassured that when Mommy came home, that I could hug and kiss and snuggle them as much as possible. I thought the Geiger reading would provide me that clarity. It came to great surprise when I requested this reading that my Radiation Oncologist and the Physicist that administered the RAI to me said it was not standard protocol to do that reading before sending patients home but that if I wanted to come in and have one for my own personal reassurance I could come in and they would gladly do it given my young babies at home.

When I came in to the office yesterday, the physicist said that my readings were first low, then high. She then went and got another Geiger machine to do a reading in case that one was not operating correctly. It said 1 meter away from me that my levels were at background level that is safe to the general public but that near my neck was still closer to 2 which was higher and that I should consider not holding my baby skin to skin, for long periods of time for 7 more days.

As you can imagine, this was a shock to me. Had I not come in and pushed for this reading, I would be home potentially exposing my children based on what you are saying? So yesterday I could come home but today I

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E-RIDS- ADM-83 all = D-B Howe (DBH) can not. My mind went a million directions but most specifically, how I am going to ask my in laws, aunts and other family and friends to watch my infant son another week because of this news? Can I sleep with my husband? Should I stay back in isolation to stay away from my 2 year old? Do we need to extend the meal train that was set up for us?

I was devastated. Because of my experience, my social worker came in and request the manager of the physicists to come in along with the Director of all physicists for the hospital system in the state of Florida. He told me that the reading the first physicist did was correctly but she was giving me ultra conservative advice due to my infant and young child and that in his opinion, I could go home and hug my children. Clearly, this area is too gray. The rules are not black and white and they shouldn't be left up to the patient to interpret. We are coming to the hospital trusting you all as experts to tell us what rules to follow so we can prepare our families to help us during this time and take care of ourselves according to your rules. The emotional turmoil that I experienced yesterday of first not being able to go home then being able to was totally unnecessary especially given all that I have been through. Anything that I can do to help ensure there are better guidelines that are more clear, direct, specific for when patients should be released after RAI, especially special direction and instructions for pregnant/new mothers with infant children, I want to be help or be apart of to the fullest extent.