

March 2010

Dear Dr. McArthur,

*This is Angela Sergio Cleary and I am an Italian woman living in the United States. I am one of Dr. Calabresi's patients, I live in the state of Connecticut and I come every month to the Hopkins outpatient center to receive my Tysabri infusion. My husband and I drive four and a half hours to come to Hopkins every month and we have been doing it for the past 14 months. I love the care that I have been getting at this hospital but I have noticed some areas in need of improvement.*

*Quite some time ago, the nurses at the infusion center had mentioned that the room where I get Tysabri was to undergo a renovation to make it more comfortable and more welcoming to patients. I had felt the need for this to happen from the very beginning because I felt that the room was too small and too cold and impersonal.*

*Then, when I started noticing that patients in wheelchairs had difficulties entering the room, I started feeling concerned about their well being and their emotional state.*

*I saw concerned parents feeling sorry for having to move things, asking people to stand and move out of the way of the wheelchair and apologizing for bothering others.*

*I would think that, given the nature of the center, the infusion room should be more accommodating to patients with disabilities. Johns Hopkins is one of the elite institutions in the country and in the world but you don't really see this when you enter the infusion center. I don't think anyone should be apologizing for being in a wheelchair and I feel that this needs to be addressed.*

*I can understand that there might be a lack of funding, but we shouldn't put money before people. In fact, isn't part of Johns Hopkins mission to put its "patients first"?*

*I am aware that there are more than hundred people that come every month to take Tysabri and I think we all deserve a better environment for our care.*

*I have done my own personal survey talking to the many patients that I got to meet in the past year and I found out that everyone is really interested in having better food/snack choices and that we feel that it goes against our desire and need to get healthier to eat items that are filled with preservatives, fats and sugars so we would all love to have healthier alternatives like nuts, raisins, fresh fruits like apples and bananas and some all natural and organic choices.*

*It goes against a hospital's mission to offer unhealthy, processed food items to its patients and I feel that it would be better if the care would include every aspect of our health.*

*Also, every time I go back to my homeland, which is Italy, I see first hand that people are truly involved in recycling to help the environment. This made me think that it should be important for a health care center and hospital to do as well. I think that adding a recycle bin for plastics and cans would be really appreciated because I always*

*drink a lot of bottled water during my infusion and I always feel bad throwing it in the garbage can with other items because I know that it won't be recycled. I am sure I am not alone in this.*

*I feel that a hospital the caliber of Johns Hopkins should be ahead of the curve in terms of this aspect of care, to set an example for other hospitals to follow. Speaking with my friends around the world, I know that this is possible.*

*I hope this is helpful and the renovation on the infusion room will begin shortly because I feel that this is very important. It truly breaks my heart to see people in wheelchairs navigating through narrow doorways and around corners and it breaks my heart to see their expressions on their faces. They are already going through enough and they shouldn't have to worry about this as well.*

*Thank you for your time. I am looking forward to hearing from you.*

*Take care,*

*Angela*