

March 4, 2014

Dear Karen Mckeown:

I am a participant in the Wisconsin Well Woman Medicaid Program. I am currently undergoing treatment for metastatic breast cancer for which there is **no cure**.

I am writing to you as I am very concerned about the future of the Wisconsin Well Woman Program. I would also like to express how this remarkable program has had an unbelievable impact on my life.

There are many ways the Wisconsin Well Woman Program touch's women's lives. When a woman is hit with a breast cancer diagnosis it is a hard pill to swallow, a million thoughts go thru your head, "am I going to die?" "what about my children?" "how will I survive"? These are some of the thoughts women think about as they are diagnosed. These thoughts are scary, gut wrenching and worrisome. The same feelings occur when a woman discovers a suspicious lump and the women are underinsured or uninsured and may lack the ability or knowledge on how to be able to get screened or get an initial mammogram. Women in this situation are very vulnerable and many do not know where to turn.

The **Coordinators** of the WWWP are essential in assisting women trying to obtain screening services, which totals 10,000 screenings per year. The screening for breast cancer may save a life, early detection and treatment are the keys to successful breast cancer treatment. Options & resources for women in these situations are very limited and there are not many resources available. Many organizations provide educational information. Some women diagnosed with breast cancer and those in treatment do not have much emotional support or someone to give them reassurance. Women going thru the diagnosis, treatment, chemotherapy and it's side effects as well as job/financial issues do not need one more door shut in their face as the program is restructured and these women have no one to turn to for help.

The WWWP not only helps women with moving forward as far as their health care is concerned but the **Coordinators** are dedicated and committed to women they serve that are going thru a life threatening and life changing experience. I am one of the women that has benefited greatly from this program, and it has made a profound impact on my life.

I was diagnosed with stage 4 breast cancer in 2006, I went thru chemotherapy, mastectomy and radiation all of 2007. I was declared cancer free, time to celebrate right! Not so fast, a few years went by and I was diagnosed with metastatic breast cancer in 2010. I have been on chemotherapy ever since and had to deal with grueling side effects such as: gastrointestinal upset, chemobrain, anxiety, nausea/vomiting, mouth sores and so forth. Treatment has greatly affected my quality of life.

The **Coordinator** I have been working with has helped me mentally, emotionally, financially and with employment issues. When you feel like the treatment is killing you, you can speak to your **Coordinator** and hear a word of encouragement and compassion. She helped me with obtaining a used computer so I could communicate with people and

gain info on breast cancer, she helped me obtain a wig when I lost all my hair and I didn't even feel human. I was crushed when I lost my hair last Spring for the 3<sup>rd</sup> time. Thru the Treatment Access Fund I was able to get temporary help with my rent and utilities.

My **Local Coordinator** also helped me with job issues in 2012. When I was working full-time and trying to deal with chemotherapy, life was extremely difficult. I approached my employer about working part-time several times. I also provided my oncologist's documentation. Nothing mattered as my Employer dug their heels in and were resistant to allowing me to have special accommodations even though other employees had health issues and they were receiving accommodations I was turned down for this request. I had good work performance evaluations also. My **WWWP Local Coordinator** went to bat for me and was instrumental in assisting me with obtaining special accommodations and I was then able to work part-time. She also helped me in becoming a participant in the WI Well Woman Medicaid program as I could not afford the insurance premium that my employer was requiring.

**My Local Coordinator** is an advocate and is passionate about the women going thru a very difficult journey. **My Local Coordinator** provides reassurance and knowledge in the depth of the storm. None of the problems I have just mentioned could have been resolved without the help of my **Local Coordinator**. To scrap Local Coordinator's positions would massively impact the women that are suffering, dealing with the side effects of chemotherapy, financially and emotionally shot and with nowhere or no one to turn to for help they desperately need.

**Local Coordinators** have relationships with other agencies and have contacts in place that are key in assisting women like myself in securing services that are essential in dealing with this life changing breast cancer journey. **Local Coordinators** make all the facets of the program work together, they are the glue that holds the program together. Without these Coordinators women would be seen as just another number, and there would be thousands of women that would go undiagnosed, untreated and/or unscreened and more Wisconsin women would **DIE**. Right now 29,000 new cases of breast cancer are diagnosed in Wisconsin yearly. Without the **Local Coordinators** the number of breast cancer cases could sky rocket. Cutting back the WWWP could evolve into a lack of education for poor women, inability of women to get screened, inability of women to have case management and a lack of accessible providers. It would be a devastating snow ball effect and it would cause great pain to the women that are newly diagnosed and those currently in treatment that would have no one to help them navigate thru the complicated healthcare system and terrible impact the disease is having on them.

**I am very worried** about how the restructuring of the program will impact my situation going forward as I am terminal. I have very little money, and I experience side effects due to the chemotherapy treatment I receive, sometimes I have to go to food pantries to survive. It is a rough road and I am very concerned that if this program is discontinued or restructured quickly without considering the women it is impacting that I will be out of luck. This restructuring dilemma is causing me as well as others a lot of stress and that is not good for our health. I am a college graduate and I would not wish this situation on anyone, I did not sign up for this.

I am also concerned if the program is reorganized that there will be no providers or if you have a provider a participant may have to drive long distances to get to the provider's office, thus transportation becomes an issue and you have to start all over with a new Oncologist that perhaps does not have the same level of knowledge, background or expertise as the one you had. Have you ever had to change doctors when it was your employer's choice - not your choice?

The idea of restructuring may seem good on paper, but women are to be valued not thought of as a commodity. The WWWP has been very successful in helping women deal with breast cancer for 20 years. When a program is helping women maintain life while going thru treatment why does it need to be changed? I understand it may be the cost involved in running the program. But if it has to be restructured why can't it be gradual over a 5 year period so women would not feel like they are in free-fall mode as their life is tipped upside down.

For example: picture this, you or someone you know has been diagnosed with breast cancer and has been going thru treatment for 8 months and you receive a notice in the mail you no longer have a provider and one more thing you no longer have a coordinator/case manager all within 6 months of this notice. How would you feel? I can tell you, it's like going from the frying pan into the fire. Don't you think women going thru treatment have enough stress?

So in closing, restructuring this program would cause a domino effect to occur in the lives of women needing screening and who are afflicted with breast cancer. All areas of a woman's lives would be affected by changing of the Wisconsin Well Woman Program as it now exists. I am pleading with you today to think long and hard about reorganizing this program haphazardly and quickly as lives of Wisconsin women are on the line, 29,000 and counting.

**Women do not represent numbers or dollar signs** on a page, so please if you are planning on restructuring the program do it in a way that is gradual over a 5 year period so women can come to grips with the change rather than feeling like they've been thrown out of an airplane. As I see it there needs to be room for compromise as these are WOMEN'S lives we are talking about here .

For 20 years the WWWP has screened women, saved lives and valued the unique qualities of each woman's life it has touched. Making drastic cuts would cause an immense amount of stress on the compromised participants the program serves. It would also signify that the State of Wisconsin does **not** care about the health care needs of the women of Wisconsin.

Sincerely,  
DS

Cc: Governor Scott Walker  
Cc: Susan Uttech  
Cc: Cynthia Musial