

A Preemie's Bill of Rights

by Read McCarty

I deserve... to be understood and treated as the individual I am. I deserve to have my language of cues and signals understood by you, my caregiver. My grimaces, hand stretches, frowns and hiccups are as meaningful as any words, but delivered in the only language I know.

I deserve... your recognition that I may be completing many months of my physical and neurological development outside the protection of my mother's womb. Even as you give me the life sustaining care I so badly need, as much as possible I deserve to have the boundaries, quiet, warmth, gentle stimulation, dim lighting and fetal positioning I would have in my mother's womb.

I deserve... periods of uninterrupted quiet so I can use my energy to grow and not hopelessly trying to overcome excess light, noise and over stimulation.

I deserve... the warmth, tenderness and comfort of being held by my parents as soon as they feel comfortable and when my medical condition allows.

I deserve... to receive the benefits of my mother's breast milk if she can provide it or donor breast milk if she cannot.

I deserve... the positive energy of love... your kind thoughts and words as you care for me... my father's soft touch... my mother's gentle words... a volunteer's quiet rocking. I deserve these things because in your heart you know their worth even though their absolute clinical value may never be proven.

I deserve... your understanding that what is normal and routine for you, as my caregiver, is abnormal and frightening for my mom and dad. So please answer kindly no matter how many times they ask the same question. They deserve your support and understanding and the support of other families as they go through the roller coaster experience of the NICU.

I deserve... your recognition that my parents are an integral part of my caregiving team and should be allowed and encouraged to the best of their ability to help care for me during my stay in your hospital.

I deserve... your understanding that part of your job is to help my family bond with me as we learn to trust each other in preparation for my homecoming.

I deserve... continuity of care from the NICU to my home... from my neonatologist to my primary care giver... so together my family and I can reach our full potential.

YOU DESERVE MY THANKS AND RECOGNITION – I AM HERE BECAUSE OF YOU!

Read McCarty is co-founder of SandBox Medical, founder and former CEO of Children's Medical Ventures and Hawaii Medical. He is dedicated to improving the health care of children and making the practice of developmentally supportive/family centered care the standard of care in the NICU.

Thanks to Olivia and her family. Please feel free to copy and share.

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