

Reflections on my CONTROL NETS experience

by Sandra Woods



Reflections on my CONTROL NETS experience. A simple task? Not so. Deep emotions are elusive creatures integral to living with NETs. It is not just about symptoms and treatments. How do you express fragile intangible thoughts about something which has changed your life? My words will be inadequate to the task. January 2017. My Dota scan results bring bad news. Progression and increased activity. What now? Go home and continue. Have patience. Don't panic. Depressed, angry and afraid I slept badly, ate poorly. Constant exhaustion. Dragging through fogged days. Alive but not living. I was not nice to be with. My brain refused to work. "NET-head" jumbled my words and confused my thoughts. I was forgetful. Cramping and diarrhea made life a misery. Numb with shock I waited to die, sure that this would be my soon-realized fate. Watching my family as we all pretended it would be okay was the hardest thing. My local oncologist and NET nurse Jenny spoke for me at RNSH MDT. I was totally unaware. Was I interested in a clinical trial? A meeting was scheduled, leaving two days to trawl the internet, scribble notes and grapple with my uncooperative brain. Huge learning curve. Thinking clearly to make an important decision was a challenge. Would I die? Would I be severely damaged, totally dependent – my worst fear? Could an impossible miracle happen – survival, feeling better, functional? A tantalizing hope. There were no promises. I was very, very scared. I had to try - to pass up this opportunity was unthinkable. Doing nothing is not an option for me. Fear and niggling doubt waged war with bravado, rationality and positivity. The emotional and physical roller-coaster whirled along unabated. Associate Professor Nick Pavlakis and clinical trials nurse Kathryn Jenkins endowed me with a quiet, understated certitude. I was in the right place, doing what life intended. A sense that life takes us down certain paths for a purpose has always been central to my way of thinking. This was my path at this point in time. News of my choice elicited looks of consternation, frozen smiles, awkward silences, embarrassed shuffling and tentative "good lucks". Eyes belied that sentiment, reflecting thoughts of last ditch efforts and certain death. "Clinical trial" tends to have an aura of negativity surrounding it, something which was not my experience. CONTROL NETS was a difficult time in my life but very positive in outcomes.

Randomized to the CapTem Lutate arm of the study, I took my first doses of chemo on 9 April 2017. I struggled to get those pills down - a mind over matter battle evolved. Timing on Lutate morning was tricky. No anti-nausea drugs until arrival at Nuclear Medicine in Sydney, a two hour drive away in peak hour traffic. Cold air vents fanned my face, even in winter. I slow deep breathed, gagging while my husband drove. I kept them down! Tiny wins. Looking ahead is daunting faced with months of treatment. One cycle at a time; one pill at a time. Amazing technology left me in awe. I pondered

what wondrous, creative minds had thought of all this and engineered it. I felt safe, nurtured and well cared for. My body went into overdrive with the drugs and radiation. Sensory perceptions enhanced. I felt spaced-out after cycle one. Vertigo. Falling down. Light sensitive eyes. A darkened, low stimulus lounge room. Loneliness. No hugs when I needed them most due to my radioactive body. Tingling pain. Frying sensations in my brain. Resolve faltered. I could not do this. Stern self-talk. I needed to do this. I would complete. Easier following cycles. Relief. Half way results of great promise. Celebration. Determination strengthened. My hair thinned, fell out in patches. Hands covered in hair, the drain clogged as I shampooed in the shower. Tears ran silently. Veins shrank. PICC lines. A DVT. Hospital. Controlling my own home treatment was so much nicer: comforting surrounds, family, friends, favorite things, music, fresh air and sunshine, edible food. My haven from a harsher world. Happy news – a great-grandchild due. I just had to still be here to hold that tiny baby in my arms. Hope replenished. Caravanning to Queensland – birthday candles fluttered as my grandson blew. Smiles. Hugs. It all seems so long ago now. Fading from memory. Surreal.

Clinical trials are vital to expanding understanding of NETS and in planning, delivering and optimizing treatment. Laboratory experimentation is limited - our NETS are diverse as are our responses to treatment. Biodynamic human systems (that's us!) provide the ultimate testing ground to turn ideas into clinical practice. We must help provide the answers to so many questions. If offered a clinical trial placement gather your courage put up your hand and say "yes please". It will be challenging, scary, often unpleasant and painful but rewarding. Altruism is not the only benefit. You will meet lovely inspiring people and test your physical, emotional and mental resilience. You may find, like I did, a different self – a brave, trusting one open to new ideas and experiences. Now, 26 months since I began CONTROL NETS, I remain stable, my liver mets too small to measure on CT, others less active, shrunken in size. Not perfect, not cured. Breathlessness, infrequent diarrhea and cramps, wobbly jelly legs that lose power, rashes, swollen lymph glands, nerve pain and dull aches remain. I still get tired and rest. Is my life ruined? Am I unchanged? No absolutely not! I am well. Undamaged. Energy and enthusiasm renewed. I jog uncoordinatedly to music at aqua-fitness class, wrestle my 16 month old great-grandson into nappies, enjoy the theatre, outings with friends, research and write social history books and a newsletter, keep up with seven grandchildren, travel, garden and self-care. A Sri Lankan safari adventure in April was very special. Do I still stress when fluff bunnies dwell in corners because I am playing cars or enjoying the outdoors as I walk the bike track? Not so much. Others things are more important. I am living! So wonderful. I dread the day it will fade away and I progress but for now there is much to embrace. Such a bitter-sweet time. Thank you with all my heart to those who gifted me this better life.