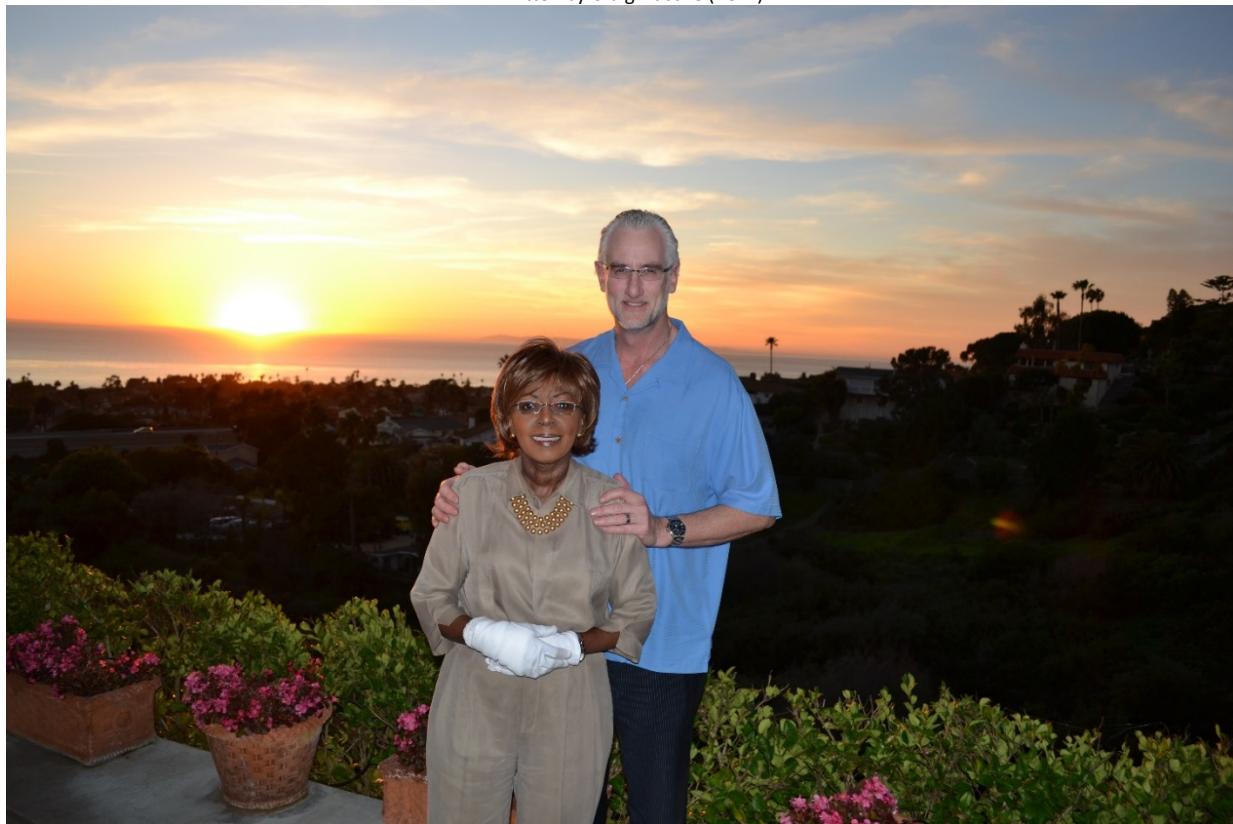


December 5, 2015

The 10 Year HISTORY of Makena's Battle, and our Battle with BREAST CANCER

~ Written by Craig Hacche (Rev2)



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The 10 Year HISTORY of Makena's Battle, and our Battle with BREAST CANCER

Makena loved her medical practice and the bond that she had with her patients. Throughout the following ten year battle with breast cancer, Makena continued to maintain her medical practice until the very end when she realized that she had to "give it up". We sent the transition letter out on September 17, 2015, and Makena passed away three days later on September 20, 2015.

The following timeline is one of battle, adventure, and a "win the day" strategy that allowed us to have just one more day of joy, each and every day, until Makena's body simply shut down.

2006 (October, the diagnosis)

Makena had just returned two weeks earlier from a trip to Kenya where we launched our 501c3 non-profit, "Answer Africa", and she had delivered approximately \$200K in medical supplies to very rural areas in Kenya. It was a Sunday, and we spent that Sunday the way we spent most Sundays. Like creatures of habit we attended Mariners Church service in the morning, we then went to a movie and then on to our favorite P.F. Chang's China Bistro for dinner at the Mission Viejo Mall.

We drove home afterwards and started to watch 60 Minutes and that is when Makena felt the lump in her right breast. I remember the conversation as if it was yesterday, and I will never forget when Makena said "I hope I am not too late" ...

Makena had a dream that night, and in that dream as she was being whisked away into an operating room for a mastectomy, the good Lord told her, "if you want to travel, you better start travelling now".

The next morning we went to the Breast Cancer Center of Orange County where they performed a biopsy. We came back later that same day and our world changed forever, as the biopsy came back as positive for Breast Cancer.

The next day, Makena had an MRI performed. The results of the MRI supported the oncologist's recommendation that all she needed to have done was a biopsy and chemotherapy.

And then Makena started her questioning and investigation process. A questioning and investigation process that only an MD would know how to pursue. And it was during that MD questioning and investigation process as it pertained to the reading of the MRI that Makena found out that the Radiologist had changed their initial MRI reading to conform to the Oncologist's opinion. AND THAT IS WHEN ALARMS WENT OFF and Makena quickly realized that SHE WAS IN THE WRONG PLACE.

So Makena demanded her medical records and biopsy slides and started a triangularization pursuit for the correct treatment and protocol. Makena flew to Stanford Cancer Center for a second opinion. Makena flew to MD Anderson for a third opinion, and we drove to UCSD for a fourth opinion.

Both Stanford and MD Anderson convened separate tumor boards. And Stanford told Makena that they could look at her from across the table and see the peau d'orange on her right breast, and tell that she had inflammatory breast cancer. They gave her a 50-50 chance of survival and basically told her that that she would need to "get the heck out of orange county" for treatment if she wants to have any chance at beating this disease. So that is what we did.

From that point onward, Makena chose to have her protocol for cancer therapy driven out of MD Anderson in Houston, TX. And she would fly back to MD Anderson every 3 months for almost 10 years and have the full battery of tests performed each time. MRI, PET/CT, bloodwork, etc.

2007 (the first full year of the ten year battle)

The first year of breast cancer treatment included a chemotherapy regimen every week for one year. And we chose to do that at UCSD in La Jolla, CA. Initially, UCSD refused to do the MD Anderson recommended protocol for chemotherapy, stating that "it would damage her heart". Makena then circled her wagons and basically convinced UCSD to do the MD Anderson protocol on her. That therapy is now standard of care at UCSD.

So every Friday morning, I would wake Makena up at 5am so that she could get ready and we would leave the house at 6am and drive to UCSD. Along the way, we would stop at the Hyatt on La Jolla Village Drive and have breakfast and then go to UCSD for the chemotherapy which would typically start at 9am. Very often friends would pick her up and "help her out". Sandy Noyes was an acquaintance that I worked with that drove Makena on many occasions. Sandy lived in southern San Diego. Sandy would get up at 4am and drive north to San Clemente and pick Makena up at 5:30am and then drive Makena south from San Clemente to UCSD. Sandy would then drive Makena home after chemotherapy from UCSD back to San Clemente, and then turn around and drive herself back home from San Clemente to southern San Diego. AN ABSOLUTELY AMAZINGLY GENEROUS PERSON.

In January 2007, both Makena and I would attend a week-long retreat put on by the Simonton Cancer Center in Santa Barbara, CA. For over 40 years, the Simonton Cancer Center has been a leader in the scientifically proven mind-body approach for treating cancer patients. The Center's integrated program was the first of its kind in the world, and was pioneered by the physician most often considered the "father of mind-body medicine for cancer patients," Dr. O. Carl Simonton, MD.

In February 2007, Makena and I flew to MD Anderson for three weeks to have the first of Makena's two mastectomies. They removed her right breast and the effected surrounding lymph nodes. Makena also chose not to have the right breast reconstruction as she did not want any possibility of infection or "blurring" of a recurrence by a right breast implant.

From February 2007 onward, Makena never took a plane flight without a compression garment on her right arm as she was adamant about the fact that she was not going to develop the painful swelling and lymphedema which often occurs after a mastectomy and lymph node removal.

In May 2007, and in addition to the weekly chemotherapy, Makena underwent six weeks of daily radiation therapy at MD Anderson in Houston Texas. We booked her a room at the Rotary House, a hotel that is attached to the MD Anderson Cancer Center. Makena would live there for the next six weeks. I set her room up with a laptop and a printer so that Makena could continue to consult with her own patients. Makena would do phone consults with her patients in Orange County, CA, under the guise that she was out of town attending a medical conference. And no one was ever the wiser. Makena also enrolled herself in daily yoga classes to help her to cope with the stress during this period.

By the end of 2007, after the one year of weekly chemotherapy, the right breast mastectomy, the six weeks of radiation treatments, and the countless flights and visits to Stanford and MD Anderson to ensure that all was going as planned, Makena was declared "NED", or No Evidence of Disease. A result that we were ecstatic about after a very long and arduous and scary year.

2008 (preventative measures...)

Makena's mindset was decisive like the surgeon that she was. Makena decided to surgically remove absolutely everything ***that could be*** removed, that could ever possibly be infected by a cancer metastasis.

Therefore in early 2008, as preventative measures, Makena chose to have the left breast mastectomy and reconstruction of her left breast during a two week trip to MD Anderson. And during another, separate two week trip, Makena also had a radical hysterectomy, to include the removal of her ovaries.

Makena also travelled to Chicago, and attended the Block Center for Integrative Cancer Treatment. This medical practice that was founded over 30 years ago with the belief that the treatment efficacy of conventional medicines can be enhanced when used in combination with supportive therapies such as a personalized nutrition plan, nutritional pharmacology, botanical medicine, psychosocial support and improved physical conditioning. The Block Center empowers their patients to become more nutritionally, physically and psychologically fit to better fight cancer. Makena wanted to ensure that she covered all bases and was 100% committed to everything and anything that could be done to prevent a recurrence of this breast cancer.

2009 (travel and Makena's 50th Birthday!)

2009 was the year of Makena's 50th birthday. So in addition to the trips to MD Anderson every three months for the PET CT, MRI and bank of tests, when I asked what she would like to do and where she would like to go for her 50th birthday, Makena didn't even think twice when she said Paris!

So off we went for two weeks in Paris where we stayed in a hotel on the Champs-Élysées and took daily tours all over France. We toured the Normandy Beaches of D-Day, Monet's home and garden in Giverny, the monastery at Mont Saint-Michel, Versailles, and of course the Eiffel Tower! And just about every single museum in Paris to include The Louvre, National Museum of Modern Art at the Centre Pompidou, the Musée d'Orsay , the Petit Palais, the Rodin Museum, Musée Picasso, Carnavalet Museum, National Museum of Modern Art in Paris, Musée de l'Orangerie, the Musee Petit Palais, Musée Marmottan Monet, Musée du Luxembourg. Musée de Montmartre. We even had our portraits done up on Monmartre.

It was nonstop go, just like Makena!

2010 (travel and the recurrence)

2010 Included two European Cruises, the Baltic Sea Cruise and the Black Sea Cruise.

On the Baltic Sea Cruise we started in London and then left from Dover, England.

We toured Copenhagen Denmark, Berlin Germany, Tallin Estonia, St. Petersburg Russia, Helsinki Finland, and Stockholm Sweden.

On the Black Sea Cruise we started with 5 days in Athens Greece, then on to Mykonos Greece, Volos Greece, and Thessaloniki Greece. We cruised the Dardanelles and the Bosphorus, and we visited Sinop, Trabzon, Istanbul and Ephesus Turkey, Sochi Russia and the Ukraine.

We met Carol Young and Grace Moore at a dinner event at the Maiden's Tower in the middle of the Bosphorus. The Maiden's Tower, also known as Leander's Tower since the medieval Byzantine period, is a tower lying on a small islet located at the southern entrance of the Bosphorus strait 200 m from the coast of Üsküdar in Istanbul, Turkey.

This new friendship with Carol and Grace would prove invaluable, and indispensable as we consulted with them on every move when the cancer returned. Carol and Grace were scientists that had contributed in many ways to this country, including work with the Atomic Energy Commission at the Nevada test site. This service resulted in Grace contracting a rare cancer associated with high levels of radiation exposure. As a long time survivor, Grace would help with research for Makena's specific disease. Grace is registered at the Atomic Testing Museum, a part of the Smithsonian, in Las Vegas, Nevada. They have also travelled extensively throughout the world.

It was during this Black Sea Cruise that Makena noticed that the left side of her neck was swollen.

When we arrived back in the United States on Friday October 29, 2010, Makena scheduled an immediate appointment at MD Anderson for Monday November 1, 2010.

We spent Halloween Sunday October 31st up in San Francisco, CA. We dressed in our elaborate costumes and went "Trick or Treating" with our nieces and nephews. That evening, I flew the red-eye to Chicago for a work related event and Makena flew the red-eye to Houston for her Monday appointment at MD Anderson Cancer Center. We spoke on the cell phone as we boarded our separate planes.

MD Anderson would perform a biopsy of Makena's swollen neck and the biopsy returned as a positive recurrence of breast cancer. The battle was back on. It was yet again time to "suit up" for the fight.

We drove down to UCSD again to interview Makena's former oncologist and Makena did not like the "hora" of the surroundings and the staff. Much had changed there in the previous two years and Makena decided it was time to find another local oncology support site. Outside of Orange County, but within commuting distance from San Clemente, CA, where we lived.

Makena then discovered an Oncologist that had graciously helped her very early on in 2006 before she first started her breast cancer treatments. I was going through the mail one day and I saw a brochure from the USC Norris Cancer Center, and just as I was about to throw it into the trash I thought that Makena might like to read it. So I placed it on the couch in the spot that I placed things for her to review. Makena picked it up that evening and flipped it open, and there was Dr. Debu Tripathy, M.D.'s smiling face. And Makena instantly knew that it was going to be USC Norris Cancer Center where she would continue her local fight with this recurrence of breast cancer. Makena would continue the quarterly visits to MD Anderson Cancer Center in Houston, however she would have local chemotherapy and oncology support at USC Norris Cancer Center with Dr. Debu Tripathy, M.D.

Near the end of 2010, Makena also researched and sought out assistance from an amazing retired OBGYN in San Diego by the name of Dr. Paul Brenner, M.D., Ph.D. Dr. Brenner is currently associated with the San Diego Cancer Research Institute, and is the author of many books to include *Buddha in the Waiting Room: Simple Truths About Health, Illness, and Healing*.

Dr. Brenner's advice and support and knowledge and friendship was a major factor in Makena's continued fight. I remember when we met with Dr. Brenner at his townhouse in downtown San Diego on a very rainy day in late December 2010. We went to eat lunch after our meeting and he told me to order the macaroni and cheese with ham pieces because it was so amazing and he wanted to see my face when I ate it.

Dr. Brenner was a wonderful friend and confidant for Makena as she prepared to battle the breast cancer again and throughout this continued battle.

As 2010 was coming to a close, the skin on Makena's right hand started to sluff. It was a very strange display of something that was about to go very terribly wrong. And would, in fact, eventually lead to Guillain-Barre syndrome, paralysis from the waist down, and an almost inevitable right hand amputation in 2011.

Guillain-Barre (gee-YAH-buh-RAY) syndrome is a rare disorder in which your body's immune system attacks your nerves. Weakness and tingling in your extremities are usually the first symptoms. These sensations can quickly spread, eventually paralyzing your whole body. In its most severe form Guillain-Barre syndrome is a medical emergency. Most people with the condition must be hospitalized to receive treatment. The exact cause of Guillain-Barre syndrome is unknown.

We spent New Year's Eve 2010 day and evening at home. Makena was lying on the couch with her right hand coated with a medicinal cooling substance. And she was in tears as the nerves in her right hand were on fire.

We met our good friends, Debbie and Jim Dower, for brunch the next morning New Year's Day 2011. We met at the Montage Hotel in Laguna Beach. Makena wore gloves to cover up the sluffing on her right hand. Makena wore her silk Bobbi Burns clothes and looked absolutely stunning as usual.

And we had no idea of the grueling and arduous battle with breast cancer that Makena was about to begin...

2011 (the toughest most grueling year ever)

As 2011 began, in addition to the hand sluffing mentioned above, Makena developed "Hand and Foot Syndrome". This was a very painful side effect of the new chemotherapy regimen and included very painful blisters all over her feet and painful nerve tingling in her hands. She also developed very painful mouth sores inside her mouth and on her lips.

I would rub huge gobs of Bag Balm on Makena's feet in both the mornings and evenings to help relieve some of the pain. The mouth sores were extreme and the blisters on her lips were getting out of hand. I remember going to Rite-Aid early one morning to get some dark lipstick to help cover the lip sores from her patients that she was to see that day. And the only color that would work to even remotely cover the lip sores was "goth". It was a strange experience...

The sluffing of the right hand continued and started to ulcerate over the entire right hand. This hand condition was eventually diagnosed as Pyoderma Gangrenosum. This was a rare skin disorder of unknown origin. Major symptoms include small pustules that develop into large ulcers at various sites on the body.

The treatment for Pyoderma Gangrenosum included twice daily bandage changes with various topical steroids to be applied twice daily. These were very elaborate bandage changes that took approximately 2 hours each time. There was soooo much throbbing pain involved and such an elaborate cleansing process that the whole bandage changing process would take two hours and the final bandage would look like a giant Mickey Mouse hand. I used to get up on weekdays at 4am to bleach down the bandage dressing site in the master bathroom. Then I would wake Makena and we would start the process. Sometimes she would scream with

pain so much that I was amazed that the neighbors never called the police. We would complete the dressing change process by about 6:30am each morning, Makena would go back to bed and I would start my workday.

The evenings were just a duplicate of the morning, and another two hour elaborate dressing change process. We would then watch TV for a couple of hours and then go to bed and start the whole process over again the next day. On some weekends or when I had to be out of town for work, my sister, Laurie, who was a paramedic, would come and help with the dressing changes. This went on every day, twice per day, from early January 2011 through November 2011. And all this time Makena continued to drive herself to work and continue her medical practice. When patients would ask about the giant Mickey Mouse bandage on her hand, Makena would say that "she burned herself while welding a piece of art with an acetylene torch"...

An interesting note, as the bandage change process became more and more elaborate we needed to find a glove that we could place over the bandages. And the glove needed to be very soft and cotton and we would need to have a new sterile glove twice per day for each new dressing. I purchased various gloves all over the internet and nothing would work. Then one day we were driving by the local mortuary in San Clemente, the Lesneski Mortuary, and Makena asked me to pull over. She then got out of the car and walked into the mortuary and came out with five pairs of large white pallbearer gloves! And Makena was laughing hysterically with a big smile on her face.

I asked Makena "what was so funny"? And Makena shared that when she walked inside the owner was there and she asked him if she could buy some of those soft white cotton gloves. The owner handed her five pairs, and when Makena tried to pay for them the owner smiled and simply handed Makena his business card and said "if you don't feel well one night, just put my card underneath your pillow"! What a wonderful sense of humor in such a traumatic time in her life.

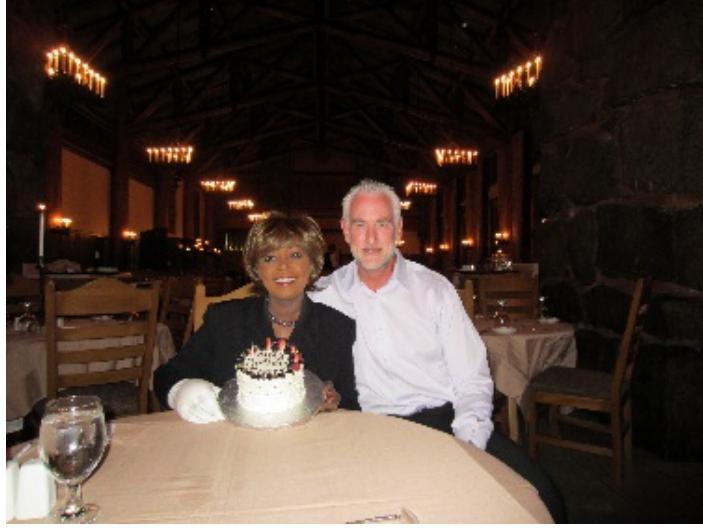
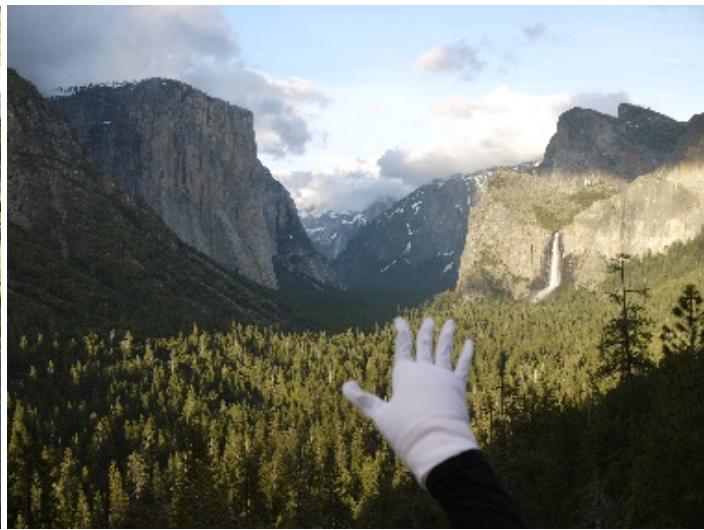
And the white pallbearer gloves worked perfectly. They were sterile, they were breathable, they were cheap and I ended up starting an account with a funeral supply company and purchased hundreds of these gloves that year. We would keep emergency boxes of them in each of our cars. In fact, to this day, I still get mailings to our home address from funeral and mortician supply companies...😊

With the severe pain of the Hand and Foot Syndrome, coupled with the severe pain of the diagnosed Pyoderma Gangrenosum, Makena would spontaneously get nauseous and vomit throughout the day. We would always travel with large gallon size Ziploc storage bags wherever we went. I would always have a couple bags in my pocket, Makena would have a couple bags in her pocket and her purse. We would keep them in the glove boxes of each car as well as spare boxes of Ziploc bags in each car as well as in every room in the house and by each side of the bed. Makena would keep them in her desk drawer in her office as well as in each room in her office. We would preopen each bag because there is nothing worse than vomiting while you are trying to get a Ziploc bag open. We would be at a movie or a restaurant or in a store or on the street and Makena would look at me and I could tell by the look that it was Ziploc bag time. I would grab a bag, open it, hand it to her, and then shield her from the public so that she could have some privacy while vomiting. Makena would often feel nauseous while speaking with a patient and quickly excuse herself, go into the next room, and grab a Ziploc bag and vomit. She would then throw it away, wash her hands, and go back and speak with her patient. And no one would ever know what had just happened...



As the year progressed and we “battened down the hatches” and “dug in” with our new lifestyle, we decided to take a vacation for Makena’s birthday in April. Makena’s hand had now worsened to such an extent that there was no longer any skin remaining, there was nothing but tendons showing, and the dressing changes became increasingly painful.

We knew that this vacation would have to be a “road trip” because we would have to take cases of bandage supplies and gloves and ointments and tape and gauze with us. We therefore decided to tour local areas in California and we packed the van full of medical supplies, absolutely floor to ceiling, and one piece of luggage for clothing. The rest of the van was all bandages for the hand. And we set out and toured Three Rivers, the Sequoias, Yosemite, Napa Valley, and the Northern California Coast all the way up to Oregon. We had an absolutely amazing time touring these areas and hiking the trails of Yosemite, and the Northern CA giant redwood trees. And all the while still doing two 2-hour bandage changes each and every morning and evening and packing the Ziploc throw up bags everywhere we went. We made light of the hand as we treated it as our friend and took some pictures of just the big white Mickey Mouse hand with amazing landscapes behind it like Yosemite Half Dome and Yosemite Falls, and the Sequoias and Napa Valley, the Giant Redwood trees of Northern, CA, and the rugged coastlines of Big Sur and Carmel and Monterey, CA.





An interesting story when we checked into The Ahwahnee Lodge in Yosemite National Park. Makena had pre booked the Queen's Suite where Queen Elizabeth had previously stayed. This was a wonderful suite with a private view of Yosemite Falls and the rainbows that would take place in the mist of the falls every morning at sunrise. When we drove up to the lodge, we were informed that we would need to take everything out of the van, else the bears would destroy the vehicle to get in and get anything inside the van. I remember thinking to myself, "oh my, I have a van full of bandages and medical supplies"... And then the valets wheeled out four luggage racks and unloaded the entire van and everyone stared at us as we entered the hotel and checked in with this HUGE amount of bandages and medical supplies. We then filled Queen Elizabeth's suite with these supplies! We had fun joking about how "if Queen Elizabeth knew what was going on in her suite, she would scream!"... 😊

When we returned home after this trip, we were "road-ed" out. Lugging cases of bandages in and out of hotels for 2.5 weeks and sterilizing hotel bathrooms all over California was an exhausting and yet amazing experience. And we had a wonderful time.

The day we drove home was the same day that my manager, Craig Winterland, had a going away party at the house of my current manager, Paul Steiner. We drove straight to the event and changed in the car as Makena wanted to personally thank Craig Winterland for all of his amazing support and understanding that he and Rockwell Automation had provided to us during these challenging times.

A few weeks later in late April or early May 2011, Craig Winterland invited us to his MBA Graduation ceremony at USC. That late afternoon as we were getting ready for the event, I heard some banging noises coming from Makena's bathroom. So I went in there and saw that it was Makena using a cane to try to stand up from the toilet. She had lost the ability to stand from a seated position and was thrusting the cane against the back wall behind the toilet in order to get the leverage to push off and stand up. Realizing that this was

now another issue that we had to deal with, in addition to the twice per day two hour hand bandage changes, and the mouth sores and the blisters on the feet, and oh by the way, the cancer chemotherapy, we said "tally ho" and set off to Craig Winterland's MBA Graduation Ceremony at USC.

At the event, I began to learn the new process of waiting until no one was looking, and then quickly lifting Makena up out of her seat as she could no longer stand up on her own. She would then shuffle along and act normal. And no one ever knew.

In late May 2011, it was time for another six weeks of radiation therapy on Makena's area of recurrence, i.e. her neck. By now, all of Makena's previously shared medical problems were in full bloom, the hand was worsening and Makena was close to completely paralyzed from the waist down. As we prepared for the trip, we booked a two bed hotel room at the Rotary House which is attached to MD Anderson and I started to research Home Care Companies that we would need to hire to be with and take care of Makena 24 hours/day.

So we packed four HUGE suitcases of bandages and dressing supplies and flew to MD Anderson. When we landed in Houston, it was one week before the Memorial Day weekend. Makena's quarterly appointments and tests at MD Anderson started on Monday and lasted until Thursday. We had been trying to get an appointment all week long to see a Neurologist regarding Makena's paralysis as her condition was worsening. The Memorial Holiday weekend was coming up and everyone was going into Holiday weekend mode. And the soonest appointment that the Neurologist would see Makena was the Wednesday after the Memorial Day weekend. By the Friday before the Memorial Day weekend, Makena was in really bad shape, vomiting and diarrhea had caused a 10 pound weight loss in the last three days and her paralysis was getting worse.

Makena then said "take me to the emergency room"... So I did.

And guess who we saw within two hours??? - The same Neurologist that we were not able to get an appointment to see until the Wednesday after the Memorial Day weekend. Lesson learned here. When you have a condition that is worsening and you cannot get in to see the specialist because of scheduling reasons, then just check yourself into the emergency room and short circuit the system.

It was during this Emergency Room visit that the Neurologist diagnosed Makena with Guillain-Barré syndrome (GBS). This is a disorder in which the body's immune system attacks part of the peripheral nervous system. The first symptoms of this disorder include varying degrees of weakness or tingling sensations in the legs. In many instances the symmetrical weakness and abnormal sensations spread to the arms and upper body. These symptoms can increase in intensity until certain muscles cannot be used at all and, when severe, the person is almost totally paralyzed. In these cases the disorder is life threatening - potentially interfering with breathing and, at times, with blood pressure or heart rate - and is considered a medical emergency. Such an individual is often put on a ventilator to assist with breathing and is watched closely for problems such as an abnormal heart beat, infections, blood clots, and high or low blood pressure.

They immediately started an EXTREMELY expensive **Intravenous Immunoglobulin (IVIG)** therapy process and Makena was then hospitalized for the Memorial Day weekend and into the next week. I then called my new Manager at Rockwell Automation, Paul Steiner, and shared the fact that my wife had Breast Cancer, and that I

would be gone for another week as there was much to set up and get ready for Makena to support her extended stay and the upcoming six weeks of radiation therapy.

I then interviewed Home Care providers and hired an excellent team of caregivers through a local company called Synergy. Synergy would supply three different people per day for the three separate eight hour shifts needed to take care of Makena 24 hours/day. I also found out that Home Care service is not covered by health insurance...

I went to Best Buy and bought Makena a laptop and printer and desk chair and set these up in her hotel room. We also had the entire hotel room sterilized with Lysol and I trained three of the Home Care service nurses on the two hour long, twice per day, bandage changing process for the hand. And I moved the four HUGE suitcases of bandages and dressing supplies into the hotel room.

I then flew home to get back to work for my employer, Rockwell. I would also handle everything that still needed to be addressed to keep Makena's medical practice afloat. We needed the additional income from the medical practice in order to continue to fight the breast cancer in the manner and with the intensity that it needed to be fought.

Makena was then released from the MD Anderson Hospital to her caregivers and she moved into the hotel room that had been sterilized and prepared for her to live in and work her medical practice out of by telephone. She again told her patients that she was out of town at a medical conference.

And no one ever knew...

As the radiation therapy process started, Makena would insist on shuffling to and from the hotel room to the radiation therapy location at MD Anderson. Makena would shuffle this approximate $\frac{1}{2}$ mile round trip and push her own wheelchair for support. She did this as she wanted to aggressively fight the Guillain-Barré syndrome and to do everything that she possibly could to beat the paralysis. Makena also registered in daily Pilates classes and daily physical therapy in order to ensure that she left no stone unturned. They also started the weekly steroid injections in her hand which consisted of 24 separate injections all around the perimeter of the ulcerated hand, another EXTREMELY painful process.

Another interesting story... Makena's daily physical therapy was at 7am every weekday morning before the radiation therapy. The caregiver would wake Makena up at 4:45am, perform the elaborate hand dressing change, pick Makena up on her feet, and then walk with Makena while Makena pushed her own wheelchair the $\frac{1}{4}$ mile to arrive at the MD Anderson Physical Therapy Center by 7am. There were two bicycles at the Physical Therapy location and Makena wanted to ensure that she got on a bike each day. A few of these days, the Physical Therapist was late, and Makena lost the ability to get on the bicycle that day as other patients beat her to it. Makena then read the Physical Therapist the riot act and told them that if they could not be on time then she wanted another Physical Therapist that could be on time as she would not stand for their lateness that would cause her to miss the opportunity to get on the bicycle. The Physical Therapist was never late on Makena again after that conversation...☺

Makena then settled into a steady state with the paralysis and the hand and the radiation and all of the cancer and IVIG and physical therapies. This schedule would absolutely consume all day, each and every day of the week. **Makena was then crushed by an overhead gate inside a pharmacy while sitting in her wheelchair...**

It was 7pm on the Friday before the July 4th Holiday weekend and it was shift change time for the Synergy caregiver. The new caregiver was running a few minutes late so Makena told the existing caregiver to just go ahead and leave her at the pharmacy entrance while she waited for her prescriptions and the replacement caregiver. After all, she was in a safe place, what could possibly go wrong??? Sadly, after the existing caregiver left Makena alone, the pharmacist decided to close the pharmacy and flipped the switch that would close the overhead steel cage door that would close the entrance to the pharmacy. Even more sadly the steel gate did not have any sensor safety mechanism that would have prevented it from closing if anything was in its path. So the overhead steel cage door closed down right on Makena's left shoulder and ground her into her wheelchair. Makena started to scream, the pharmacist heard the scream, and came running out to find Makena trying to work herself free from the powerful overhead steel cage door that was continuing to grind Makena into her wheelchair. Makena was eventually able to work herself free, and the pharmacist realized what was happening and reversed the door switch mechanism. A police officer that was stationed around the corner heard Makena's screams and came running.

Makena was then taken to the emergency room where they took X-Rays and determined that there were no fractures or damage. But something was seriously wrong as Makena could not move now without EXTREME screaming pain. It turns out that the X-Rays were misread and Makena actually now had eleven (11) spinal compression fractures and two (2) broken ribs and we never realized this until two months later in late August 2011.

Not knowing about the eleven (11) spinal compression fractures and the two (2) broken ribs, Makena continued with her radiation therapy and her hand therapy and her Pilates and physical therapies. And everyone chalked up the new EXTREME screaming pain to muscle soreness caused by the overhead steel cage door.

I then flew to Houston in mid-July to pick Makena up and bring her home. Makena told me to meet her in this new cafeteria where they had great fresh salads that I might like. And I will never forget the moment when I saw Makena walk towards me pushing her wheel chair with a big steroid induced puffy face and tears in her eyes...

I spent that evening packing all of Makena's belongings after the hand bandaging process and we went to sleep. We would then wake up at 2am with a new challenge. Makena was now completely incontinent as the Guillain-Barré syndrome had progressed north in her body to such an extent that she no longer had control of her bowels. This happened at 2am and again at 4am. And then we were up again at 4:30am to do the hand bandage change and get Makena to her last physical therapy session at 7am.

So here we were, getting ready to fly home to San Clemente, CA. Makena's radiation therapy was complete but her hand had continued to worsen and decay over the previous six weeks, her Guillain-Barré syndrome had progressed North in her body to such an extent that she no longer had control of her bowels and had to

wear a diaper, she was still paralyzed from the waist down without the ability to stand on her own, she had massive diarrhea all the time, she was vomiting all the time, and she was in an EXTREME amount of additional pain without the ability to move without screaming due to the eleven (11) spinal compression fractures and two (2) broken ribs that were yet to be diagnosed.

And neither Makena's patients nor anyone ever knew....

On the flight home we knew that we had a long and hard road ahead of us if we were to prevail in this fight and that we really needed to remain aggressive and focused in our continued pursuit to win. And the first priority was the decaying hand that was quickly becoming the most EXTREME of the many emerging medical emergencies that Makena was displaying.

1. August 2011

- a. The hand continues to decay, Makena consults with Carol and Grace and they decide that we need to focus all of our efforts on the hand right now as the tendons are now fraying and it is continuing to get worse. They research Pyoderma Gangrenosum and find that it was first diagnosed by the Mayo Clinic in Rochester, MN.
- b. Makena and I fly to the Mayo Clinic in Rochester, MN, and land there on Sunday 8-21-2011. A day I will always remember as that was our 12th Year Wedding Anniversary.
- c. The Mayo Clinic in Rochester, MN, is probably the most amazing and comprehensive and integrative facility in the world. And by this time, we had been and flown just about everywhere.
- d. The Mayo Clinic immediately discovers the reason that Makena is in so much screaming pain. And they do it by reading the same x-rays that were taken and sadly misread by the previous medical facility, and they inform us that Makena has 11 compression fractures and two broken ribs.
- e. The Mayo Clinic then sends Makena for a custom fitting for a clam shell type back brace. A back brace that is very claustrophobic when worn.
- f. Dermatologists at the Mayo then analyze Makena's hand and inform us that Makena never had Pyoderma Gangrenosum, and that she should immediately stop the steroid therapy that she was instructed to do as it was an incorrect diagnosis and was actually the reason that the hand was continuing to worsen and also very probably the reason that she had developed Guillain-Barre syndrome. And the extent of the damage to the hand was actually iatrogenic, meaning "human caused" or "of or relating to illness caused by medical examination or treatment".
- g. An amazing Plastic Surgeon by the name of Dr. Steve Moran at the Mayo Clinic informs Makena that they can save her hand but they cannot do a skin graft directly on top of tendons as the skin will stick to the tendons and Makena would then lose the use of her right hand. However there was a new product out called Integra. Integra could be sewn over the tendons and directly to the hand. They would then pull a sterile vacuum on the hand for two weeks, and then perform a skin graft over the Integra. The Integra would thereby create a lattice network for the skin graft to attach to and heal without effecting the tendons. The entire procedure would take at least 8 weeks. And, even better, that Makena did not have to do it away from home while at the Mayo Clinic as there was an Integra specialist at UCSD in San Diego, CA! To which we said, "Praise the Lord"! And "Hallelujah"!
- h. So we flew home and scheduled an appointment at UCSD for the following Monday.
- i. Makena's best friend, Janice Casoria, picked Makena up early on Monday morning at 5:30am and drove her down to UCSD. When I came home that evening, Makena and Janice were sitting

on the couch, Makena was in a full sized Velcro back brace and sitting up very rigid and in tears. And Janice looked to be in shock.

When I asked how the day went, they shared the following:

- i. When they arrived, Doctors at UCSD had Makena fitted with a velcro back brace for the 11 compression fractures and two broken ribs.
 - ii. However, when they met with the Integra specialist at UCSD, the Orthopedic Surgeon looked at Makena's hand and simply pushed it away in disgust. He then looked at Janice and told Janice, and I quote, "that she should take Makena to see a psychiatrist because she would need to wrap her brain around the fact that her right hand was not savable and that she would need a right hand amputation."
 - j. Makena and I then looked at each other and we both thought and said, "Whelp, we DO NOT like that answer at all, in fact we like the answer that we received at the Mayo Clinic much better"... So Makena then picked up her cell phone and immediately called Dr. Steve Moran of the Mayo Clinic on his cell phone. This is now about 11pm Rochester time. Dr. Moran answers his phone, and Makena informs him of the events of the day. And Dr. Moran says come on back to the Mayo!
 - k. I then book two more flights back to the Mayo for the next morning and we spend the evening scrambling to pack Makena's bags for the 8 week stay that will be necessary in Rochester, MN, in order to save the hand.
 - l. We arrive back at the Mayo Clinic on Tuesday evening and we meet with Dr. Steve Moran the next Wednesday morning and they immediately schedule the Integra surgery for Friday morning.
 - m. I hire a wonderful Nigerian lady that had previously helped to take care of Makena when Makena was at MD Anderson in Houston earlier this year and I fly her out to Rochester, MN, to take care of Makena for the two months needed to complete the Integra and skin graft surgeries and therapies required to save Makena's hand.
 - n. I book a two bedroom hotel suite at the Radisson Inn which is attached via an underground tunnel mechanism to the Mayo Clinic.
 - o. I go to the 24 hour Walmart at 11:30pm and shop for the supplies that they will need in order to hunker down in the hotel for two months.
 - p. The Integra surgery is successful.
 - q. I fly back to CA and get back to work.
2. September 2011
- a. The Integra surgery goes well, a vacuum is pulled on the hand for two weeks, a 3" by 20" slice of skin is taken from Makena's right thigh and used to graft to her right hand.
 - b. The skin graft goes well and is healing well.
 - c. The right leg where the skin graft is taken from however, is not healing at all, and is now becoming a whole new and additional problem.
3. October 2011
- a. Rochester is starting to get cold and I am starting to get phone calls from the Nigerian caretaker about this as she is not used to cold climates, least of all Minnesota as they move into winter.
 - b. Makena is in EXTREME pain and miserable. Remember Makena had just finished six weeks of radiation, was still taking oral chemotherapy daily, is still paralyzed from the waist down with Guillain-Barré Syndrome, has still lost the ability to control her bodily functions and must wear

a diaper, was still only recently crushed by an overhead steel door and is now four inches shorter with 11 painful compression fractures and two broken ribs. Makena still cannot move without screaming, has a right hand that is still wrapped like a Mickey Mouse hand and still vomits into Ziploc bags that are stocked everywhere and taken everywhere she goes. And now she has a right thigh with a 3" x 20" open wound that is bleeding and will not heal...

- c. The Mayo Doctor's suspect that Makena's healing issues may be due to cancer having spread to her bones and that Makena may have now developed Myelodysplastic syndrome and they order a bone marrow biopsy. Myelodysplastic syndromes are a group of cancers in which immature blood cells in the bone marrow do not mature or become healthy blood cells. The different types of myelodysplastic syndromes are diagnosed based on certain changes in the blood cells and bone marrow.
- d. The bone marrow sample comes back as negative.
- e. And Dr. Makena still speaks to patients via the telephone and NO ONE ever knows.
- f. Makena is at her wits end, she speaks on the telephone 3-4 hours each night with her loving support system of Janice Casoria and Carol and Grace.
- g. The Mayo Clinic performs vertibroplasty surgery on 7 of Makena's 11 compression fractures and this gives Makena some instant pain relief at those levels.
 - i. This procedure consists of injecting dental cement in the micro fractures of the spine that hardens in about 20 seconds giving instant pain relief at those areas. An amazing procedure developed by some crazy French doctor a few years ago.
 - ii. Hallelujah! One less problem to deal with!!!

4. November 2011

- a. I fly back to Rochester, MN, and pick Makena up from the Mayo Clinic and bring her home to San Clemente.
- b. Makena continues to see patients in her office.
- c. Makena speaks to Carol and Grace and books a cruise for us to the Caribbean for the next month of December!

5. December 2011

- a. The Caribbean Cruise and Sea Doos!

(Sea Doos in the Caribbean)

So at the end of this year 2011, probably the most intense and grueling and tumultuous year of the first five years of the ten year fight, Makena has decided that she needed to cruise the Caribbean for Christmas with our best friends Carol and Grace! And she wanted to get on a Sea Doo!

So picture this... Makena weighs all of 80 pounds, she is as limp and weak as they come, and she is in really, really, really bad shape...as previously described.

But Makena was committed to riding the Sea Doos!

So we wrapped Makena's legs in a special plastic suit that we bought before we left on the cruise and we wrapped her Mickey Mouse hand in more plastic.

We exited the bus at the Sea-Doos site and went to board the Sea-Doos and one of the female ride monitors came running out and said to Carol and Grace with alarm in her eyes "Mam! This woman cannot ride the Sea-Doos in her condition, she looks very sick, and she needs a doctor!"

To which Carol and Grace said "she is a doctor!"

Makena overheard the conversation as I was supporting her and helping her to shuffle to the Sea-Doos and added, "not only am I a doctor, but I am a Trauma Surgeon, a Hand and Micro Surgeon, and a Plastic Surgeon, so I know exactly what I am doing!". We then quickly placed Makena on the Sea Doo and she sped off, and I scrambled to get on one myself to tail her in case of emergency...

2012 (the Right Thigh, a Stalker, Mayo Clinic in Jacksonville-FL, and another Bone Marrow Biopsy)

The strong chemotherapy coupled with Makena's lowered immune system prevented the skin donor site on Makena's right thigh from healing. The raw skin also required twice daily bandage changes. So early in the year we flew Makena back to the Mayo Clinic in Rochester, MN, for a postsurgical review of her right hand and we also had the plastic surgeon at the Mayo repair the site and surgically turn the 3" x 20" shave of skin site into a 20" cut and sew it into one long scar.

This thigh operation ended up failing at the top six inches of the incision, a minor issue as Makena had so much excess skin now due to her massive weight loss. So Makena had a surgeon at USC perform the repair under outpatient surgery. And it failed yet again, so when Makena flew back to MD Anderson in March 2012 for her Quarterly checkup and battery of tests, she had the plastic surgeon at MD Anderson make the minor surgical repair needed. In addition, the left breast implant that Makena had placed after her second mastectomy was now too big for her new 85 pound 4'11" kyphosis hunched over body, so they replaced that breast with a smaller one.

Makena still had much pain from the remaining four compression fractures into 2012 and there was still much nausea and vomiting from this pain. We still carried a good stock of Ziploc bags everywhere we went, in the glove boxes of both cars, in our pockets, in the living room and bedroom. I used to joke that we should have bought stock in SC Johnson, the manufacturer of the Ziploc bag!

The paralysis of the Guillain-Barré Syndrome began to subside in early 2012 and by midyear Makena was 75% recovered from the paralysis. Although Makena was still very weak and frail, this Guillain-Barré Syndrome would continue to affect her until she passed away on September 20, 2015.

As the year progressed, in March 2012, Makena was then subjected to a Stalker.

YES – A Stalker!

So after this incredibly challenging year of 2011, a Stalker began calling Makena's office 80 times per day and leaving very threatening messages along the lines of "You Nigger, I am going to end you", and other very abusive and threatening comments.

We called the Sheriff's Dept. and they sent a Sheriff out to gather information.

Three weeks later and numerous phone calls = NOTHING.

We ended up hiring a private investigator ourselves, a retired FBI Agent. We then located the Stalker's location ourselves, we delivered the information to the Sheriff's Department, and we prepared to place our own tracking device on the Stalker's vehicle.

We had ADT install video monitoring equipment inside and outside of her office and changed the locks to an electronic entry system so that no one could gain access to the office without being “buzzed in”. We also installed video monitoring equipment around the outside of our house.

Makena was so pissed off that she asked me to teach her how to fire a weapon, so I took her to a local gun range and had her take a “weapon safety class” and then instructions on how to safely fire a weapon. They also let her fire a shotgun, and this experience was quite comical. When Makena fired the shotgun, she was so small and light of weight, and even though they gave her the smallest shotgun at the firing range, when Makena pulled the trigger, she almost fell over backwards! We planned to come back the next week, and have her fire some more pistols and see which size and caliber would be the best for her.



Makena was determined to fight back...go figure...!

At one point, two undercover Sheriff's Department Detectives that looked like members of the rock band ZZ Top showed up at our doorstep in San Clemente and knocked the door. As Makena could see them on the video camera just installed, Makena refused to answer the door, and instead called the Sheriff's Department. The Sheriff's Department then informed Makena that these ZZ Top like individuals were in fact undercover Sheriff's Department Detectives that were working her case. So Makena let them in and served them tea!

The Sheriff's Department eventually arrested this Stalker.

As the year progressed, as previously stated, Makena still had much pain from the remaining 4 of the initial 11 compression fractures and there was still much nausea and vomiting from this pain. She could not get an appointment at the Mayo in Rochester, MN, so she booked an appointment at the Mayo Clinic in Jacksonville, FL, to get a second opinion on more vertibroplasty. So off we went in July 2012 to the Mayo Clinic in Jacksonville, FL.

When we got there, amazingly enough, my left arm started to go limp and atrophy. So Makena booked an appointment for me with a different Neurosurgeon.

It turns out that I needed to have six level neck fusion from spine levels C1 to T1 due to a compressed spinal cord, probably a long term progressive result from a 50ft. fall out the back end of a CH-46 Chinook Helicopter in the U.S. Marines in 1983. I also had to have twelve foraminotomies, two at each level. (A Foraminotomy is a medical operation used to relieve pressure on nerves that are being compressed by the intervertebral foramina, the passages through the bones of the vertebrae of the spine that pass nerve bundles to the body from the spinal cord).

I share this incident about myself as when we were in Jacksonville, FL, Makena had another near death experience. We had arrived in Jacksonville, FL, just before the July 4th weekend to meet with Makena's Neurosurgeon to see if she could get the remaining 4 of the initial 11 compression fractures repaired with more vertibroplasties. As we were there over the July 4th Holiday weekend, we decided to go to the local beach and celebrate. After returning to the Marriott Sawgrass Resort Hotel, Makena talked about how she had always wanted to learn how to swim. So I said, "Hey, we have some time, let's go to the pool and have some fun". In the pool, I told Makena, "first things first, you will need to get used to having your head under water, so go ahead and just dunk your head in the water here in the shallow end and hold your breath for a while under there" ...BIG MISTAKE!!!

We had both forgotten about Makena's ZERO immune system and the fact that kids had been swimming in that very same pool, and had very probably urinated in it.

When we got out and went back up to the room, Makena started to get sick and by the next morning, Thursday morning, was starting to run a fever. So we nursed her fever over the weekend and did the best that we could. She prescribed medications for herself at the local CVS Pharmacy and I went to pick up these medications and other supplies as we now needed to hunker down in the hotel room until I had my surgery the following Monday, four days later.

By the time Monday morning came, Makena was running a dangerous fever. As I checked in for my six level neck fusion surgery, Makena checked herself into the emergency room. When I woke up, after the six hour operation, I woke up to Makena's big brown eyes and smiling face. And Makena spent the evening in the ICU with me.

They transferred me to a hospital room the next morning and Makena came with me. The room had a lounge chair and a bed. And by this time Makena was really, really sick, there was something very seriously wrong with her as she was not recovering and it was now almost a week since we swam in the pool. I felt more comfortable in the lounge chair as I could sit up straight in the chair and also sleep sitting up. So Makena took the bed. And she made appointments to see doctors at this Mayo clinic to see why she could not get rid of this fever.

Things were getting really bad, I could hardly move, the hospital room was for me to recover from the six level fusion surgery, and when the doctors would do rounds and come in the room, they would look around at both of us and say, "OK, so who is the patient"???

Makena's condition was not improving, and in fact was getting progressively worse. The Mayo Doctors again suspected that the breast cancer may have spread to Makena's bones. This would require a second bone marrow biopsy to yet again check for the development of Myelodysplastic syndrome.

The morning that Makena left for the bone marrow biopsy I picked up my cell phone to call Makena's family and inform them that Makena was in very bad condition and I that was very concerned that she may not make it home. I then changed my mind and I decided to wait for the results of the bone marrow biopsy before making such an alarming phone call. This proved to be a good decision because when Makena came back from the biopsy, she was so pissed off at the experience that she was alive again!!!

This bone marrow biopsy turned out to a very painful experience, and in fact much more painful as it needed to be. When the Physician's Assistant and Nurses were injecting the bone marrow sample site with pain medication, they were talking amongst themselves. As they started to perform the biopsy, Makena screamed with pain, and asked for more pain medication, to which they said that they had already given her an ample amount and perhaps they should just wait a little longer. Makena said that it has been long enough, and would they please give her some more. To which they again said, let's just wait a little longer. Then, as they waited longer, they asked Makena what she did for a living and Makena told them that she was in the medical field. They asked Makena what she did in the medical field, and Makena said that she was a doctor. They then asked her what kind of doctor, and Makena said that she was a surgeon. The PA then immediately signaled the nurses and they immediately gave Dr. Makena more pain medication!!!

After this was all over, Makena walked back to my hospital room and was so pissed off at the experience that she was fully alive again! The bone marrow biopsy came back negative and we left the hospital the following Friday and went back to the Marriott Seagrass Resort Hotel and recovered and flew home on Sunday July 15, 2012. The drive to the airport and the journey inside the airport in Jacksonville, FL, was an interesting one as we were both in wheelchairs! And there was one attendant that pushed us both the whole way, one in each hand!

Interestingly enough, Makena had previously chosen to spend her 50th birthday with a two week trip to Paris, and I end up celebrating my 50th birthday with a six level fusion, two eight inch titanium rods and twelve pins, and twelve foraminotomies, two at each level. Ha! I think Makena made the better choice!

Once home, we settled in and went back to work. I hired a driver to drive me to my work related appointments and Makena went back to work. And not a single one of her patients knew any different.

We flew back to the Mayo Clinic in Jacksonville, FL, in September 2012, and Makena had more vertibroplasty surgery on the remaining 4 of her 11 compression fractures.

Makena then booked a trip to Kenya and went on Safari, and I stayed home and hired a contractor to demolish her bathroom as it needed to be remodeled due to all of the corrosive effects of the bleach on the chrome fixtures and bath fixtures and tile from the previous 2x daily, 4hrs. /day, dressing changes for the decaying hand.

When Makena returned home she booked a Christmas vacation to the Grand Canyon, Sedona, and Scottsdale. These were some sites on her bucket list.

2013 (Shingles, Throat Tumor, Paralyzed Vocal Cord, Laryngeal Spasms, Suffocation, Infected Breast Implant, and Two Brain Tumors...)

2013 started with a very painful development of shingles on Makena's back. Her weakened or zero immune system was susceptible to everything and now she had to also battle the shingles virus. In addition, her quarterly checkup at MD Anderson in Houston showed increased nodal activity in her throat and close to her left lung and her chemotherapy regimen was changed. The new regimen was another powerful drug that would knock Makena out for five days. We would drive Makena to USC on Friday, have the day long chemotherapy session, then drive home in traffic and batten down the hatches because within 24 hours Makena would be completely debilitated from the effects of the chemotherapy and this would last for five days. By the following Thursday, Makena would be back to work. And not a single patient ever knew.

Makena had her first quarterly visit of the year 2013 to MD Anderson in Houston, TX, for another battery of tests. This time the infamous PET-CT of the body that can light up a rogue cancer cell like a Christmas tree would light up and display a new tumor on one of Makena's vocal cords.

By this time, the node in the throat that showed up the previous year had grown and was pressing on one of Makena's vocal cords, and causing a squeaky voice. This is the same node that would eventually grow into a tumor and ultimately paralyze both of Makena's vocal cords in a closed position in September 2015. This in turn would eventually result in Makena's inability to exhaust her own CO₂ gasses, and lead to the requirement of an intubation tube and ventilator in Makena's final days.

Makena would now lose her beautiful and articulate voice, and it would be replaced with a very course and squeaky voice. She would explain this change to her patients as sinuses and or laryngitis. And no one ever knew.

As this new tumor grew, Makena's voice continued to deteriorate. During her second quarterly visit to MD Anderson in 2013, and after the usual battery of tests, they offered Makena a procedure that had the possibility of reducing some of the squeakiness in her voice. This would however be a very painful procedure. They would first place a small flexible wiring tube with a camera inside up Makena's nose and down into her throat. They would then use that camera to guide multiple injections of silicone through the neck in between the tumor and the vocal cord, thereby reducing the friction of the tumor on the vocal cord when Makena would speak and the vocal cord was vibrating. Makena would have to sit still and be fully awake during the entire hour long procedure. And Makena opted for the procedure. After the procedure was over, Makena stated that it was like an hour long torture session.

Makena had made the trip to MD Anderson by herself this time. And this turned out to be a big mistake. As there was a side effect of this procedure that would occur whenever Makena would cough or vomit. And Makena was still vomiting from the new chemotherapy regimen. We still carried Ziploc bags everywhere we went.

Makena woke up the next morning at 5am, was nauseous, and started to vomit. As she vomited, she went straight into laryngeal spasm, and that in turn cut off her airway and she could not breathe.

Luckily, Makena still had the presence of mind to pick up the phone and dial the front desk and make a squeak into the phone. The front desk realized that there was an emergency in progress and called the paramedics. Makena also had the presence of mind to run into the hallway and run towards the elevator before she collapsed. So there she was, on the floor, directly in front of the elevators when the paramedics arrived and exited the elevator door. An amazingly smart woman with an innate ability to have a focused presence of mind in tough and panicked situations like no other person that I have ever met.

The paramedics then resuscitated her and hauled her off to the emergency room where she then recovered.

The doctors also taught Makena a breathing technique to cope with this laryngeal spasm in the future. And that was a good thing, as these laryngeal spasms would now occur 4-5 times per week, every week for all of 2013 and would continue until the day that she passed on September 20, 2015.

These spontaneous spasms would sometimes occur when Makena was at work and consulting with one of her patients. Makena would quickly realize what was happening, quickly excuse herself from the patient, walk into the next room, perform the breathing technique, recover, and walk back in the room where the patient was, and continue like nothing had ever happened. And her patients never had any idea what had just happened...

By April 2013, her left breast implant became infected and had to be removed and Makena was hospitalized for 10 days until the breast implant was removed and the infection subsided.

Makena went to MD Anderson for the third quarterly checkup in 2013 and the results showed even more nodal activity. As this was additional cancer growth, this meant that Makena was now failing the existing chemotherapy regimen, so a new regimen was prescribed. Another butt kicker. But this time one of the Nurse Practitioners told Makena to ask a very important question that we never knew to ask before, and that question was "does this new chemotherapy regimen cross the blood brain barrier"? This is a very important question to ask as not all chemotherapy regimens work from the neck upwards, they only work from the neck downwards. So Makena asked that question when we were back at USC preparing to get the new chemotherapy regimen, and the answer was NO, that it did not cross the blood brain barrier.

Makena immediately asked for a brain MRI so that she could get a baseline on the status of her brain. She was told "that they do not just order brain MRIs on a hunch or a whim without any indications". So Makena told them that she had been having headaches. The Doctors looked at her, and smiled, and ordered the brain MRI for that same day. Makena then finished the new chemotherapy regimen and had the brain MRI. We then drove the traffic home to San Clemente and started to batten down the hatches again.

The next morning, Makena received a phone call from USC. The brain MRI had identified two new tumors in her brain. Luckily they were still small enough to radiate rather than surgically remove. Can you imagine if Makena had never asked the blood brain barrier question? Or not pushed for the brain MRI? By the time that most people show indications of brain tumors, the tumor has already grown to such an extent that it starts to press on the nerves and the lobes of the brain which in turn causes the indications. However by this time, the tumors would have very probably been the size of golf balls and would have required extensive and dangerous surgical operations to remove.

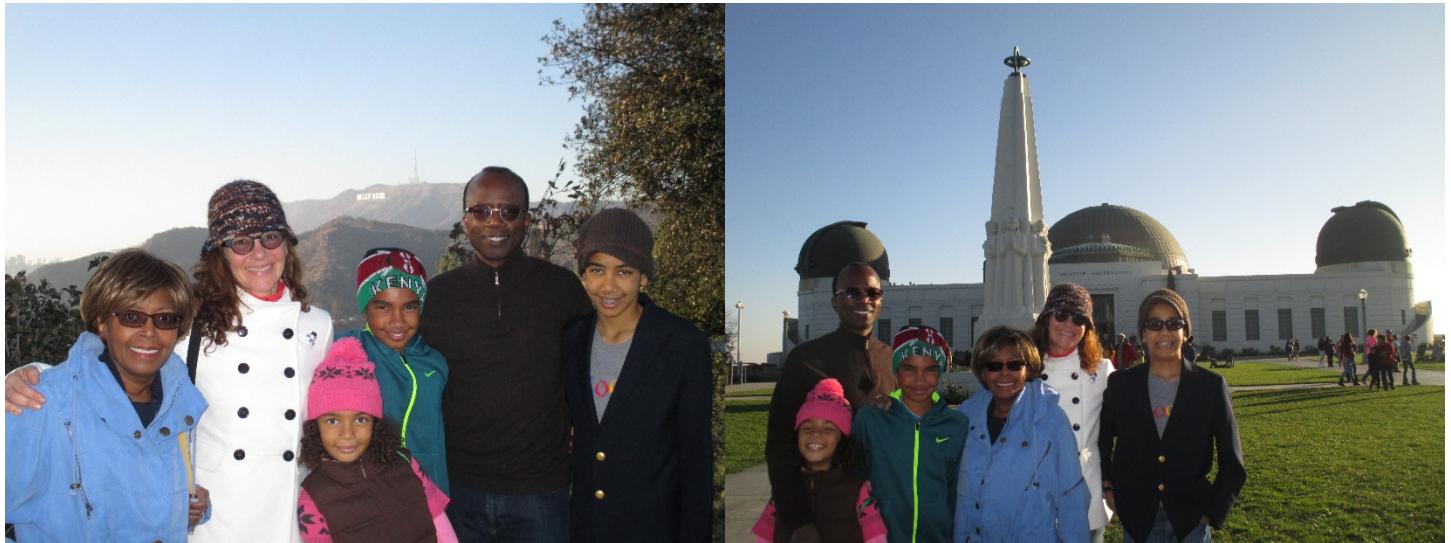
Instead, due diligence allowed us to locate the tumors early and we were able to destroy them in their infancy with gamma knife radiation. Gamma knife radiation is an amazing new type of radiation process. First the patient is anesthetized and given sedation, and a halo device is screwed into and attached to the patients head. Then the patient is fed lunch and they wait their turn for the radiation. The halo device is then bolted onto the radiation table to ensure zero movement of the patient and hundreds of radiation beams are projected through the tumor at the same time from hundreds of different angles. Each radiation beam from each different angle does not hurt the brain on its own upon entry, but when they all culminate in one location, like a magnifying glass, they burn the tumor, and then exit the other side without causing any damage to the brain other than at the point of the tumor. This is performed on both tumors. The halo is then removed, and the patient goes on their way. The following pictures show this amazing whole process.



When Makena arrives home, she goes online and books a Holland America cruise around South America. Starting in Argentina, then up to Uruguay, then down the eastern coast of Argentina to Patagonia, then to the “Southernmost Tip of South America nicknamed the Tip of the World” Ushuaia Argentina, then on to the Beagle Channel and Penguin Island, and rounding the violent and turbulent waters of Cape Horn where the Pacific Ocean meets the Atlantic Ocean at the Southern tip of Chile, the southernmost headland of the Tierra del Fuego archipelago of southern Chile, located on the small Hornos Island. Then on to Punta Arenas Chile, the Chilean Fjords, the western coastline of Chile to the Darwin Channel and Puerto Mont and then up to Valparaiso and ending in Santiago, Chile.

Interesting story...It was 5am in the morning when we rounded the violent and turbulent waters of Cape Horn. Tornado force winds had developed and the Captain of the ship ordered everyone off of the top deck of the cruise ship. By this time, Makena weighed less than 90 pounds, and when the tornado force winds developed, Makena was almost blown overboard! So I held on to her and instructed her to get down on her hands and knees. We then crawled back the entire length of the cruise ship to shelter...😊

We spent the Holiday season of 2013 at Universal Studios “City Walk” with her brother Kimathi, his wife Andrea, and their children, our nieces and nephews, Chase, Aristotle – nicknamed Tugi, and Natasha – nicknamed Bubbles. We hiked up to the Hollywood Sign, we visited the Griffith Park Observatory and watched the laser light show. We visited the Space Shuttle Endeavor at the California Science Center in Los Angeles, and we had a wonderful exciting time together.



2014 (The Heimlich maneuver, and more travel...)

2014 started with Makena's first quarterly visit of the year to MD Anderson in Houston, TX, for another battery of tests, to include the infamous PET-CT. And now each and every time Makena also insists on a Brain MRI.

Makena is invited to lunch by a Dermatologist friend that lives in Houston by the name of Dr. Esta Kronberg, M.D. As Makena is eating some wonton soup, a piece of wonton gets stuck in her throat and she starts to choke and Dr. Kronberg quickly realizes that the Heimlich maneuver is in order. As Makena stands to rush off

to the bathroom, Dr. Kronberg stops her, flips her around, and performs the Heimlich maneuver. And out pops the little itty bitty piece of wonton, about the size of a piece of rice. Esta had saved Makena's life from choking on a wonton! After all of this, all of these years of successfully battling Stage IV Inflammatory Breast Cancer, to almost get taken out by a little piece of wonton no bigger than a grain of rice!

Makena arrives home and immediately booked FIVE travel tours.

1. One in March of 2014, to Thailand, Cambodia, Vietnam, and Laos. I stayed home and Makena went with some friends that we had met on the previous South America cruise.
2. A second in April 2014 to Iguazu Falls where we visited both the Argentina and Brazilian sides of the falls. Then on to Rio de Janeiro and Ipanema and Copacabana Beaches, Sugarloaf Mountain, and Christ the Redeemer.
3. A third in June 2014 to Peru, and Machu Picchu. I stayed home and Makena went with the same friends that she travelled to Thailand with.
4. A fourth in September 2014 throughout Europe on the Viking Grand European River Cruise. We started in Prague, then Budapest, Germany, Austria, and Holland, as we cruised the Rhine, Main and Danube Rivers.
5. And a fifth in March 2015 throughout China on the Viking Grand China tour to Shanghai, Suzhou, the Terra Cotta Warriors in Xian, Beijing, The Great Wall, Tiananmen Square, and The Forbidden City, a five day river cruise down the Yangtze River, Mainland China, and Hong Kong.

The laryngeal spasms continued and Makena managed the incidents. The sheer panic in her eyes when these spasms would occur was always so sad to see. If they occurred when I was around, I would always hold her hand and sit down next to her and coach her through the breathing process to recovery. And Dr. Makena continued to see patients, and no one ever knew.

In May of 2014, Makena's right lung started to fill up again with fluid. This is what typically happens in what they call "end stage" breast cancer. The breast cancer often moves on to attack the lungs, shut them down, and support the manifestation of pneumonia, which in turn, ends the life. Makena was hospitalized at USC for ten days with a chest tube installed in her right lung to drain the fluid.

On the 9th day, a Sunday, a female oncologist that **DID NOT KNOW** Makena was on call and doing rounds that day. When this oncologist saw Makena and read her medical chart of information, she made the quick determination that Makena was in "end stage" and said "whelp, I guess that you will be going straight into Hospice when you are released".

Makena then chimed up and quickly corrected the oncologist and let her know that Hospice was not an option because she had previously booked a trip to Peru and was planning to climb Machu Picchu the next Saturday, not go into Hospice...

And true to form, Makena was released the next day on Monday, we packed her bags on Tuesday, and I dropped Makena off at LAX at 6:30am on Wednesday morning. And Makena proceeded to fly and travel by herself and get to the top of Machu Picchu the next Saturday.

In November, we attended a "Mad Tea Party" event at Disneyland. It was late at night, and Makena was very tired and could not walk very far. As she walked with me as we were leaving the park, the remaining 5% of the Guillain-Barré Syndrome acted up again and effected the lifting of her right foot. Makena tripped and fell

straight forward, down and face first onto the concrete. She was out cold. She awoke, we summoned an ambulance, and she was taken to a local emergency room where it was found that she had a brain bleed from the trauma of the fall. Makena was then transferred to USC Keck Hospital via ambulance and another battery of tests. She was released after another week in the hospital.

We travelled to San Francisco for Thanksgiving and we spent Black Friday buying our niece and nephews Christmas presents in downtown Union Square San Francisco. We ended the day with dinner at the Daily Grill. I saw Makena get up and walk to the bathroom, and I had a gut feeling that something may be wrong, so I asked my sister in law, Andrea, to please go and check on Makena in the woman's bathroom. And sure enough, Makena had just survived another laryngeal throat spasm.

Debilitating tumors started to rapidly grow all over Makena's neck. And we knew that this tumor growth was another major problem that we would need to deal with in 2015. Makena would wear scarfs to cover up the tumors from her patients and we travelled to Manhattan New York to celebrate Christmas. While in New York we visited NYU and Sloan Kettering and investigated a clinical trial therapy that would target the new tumor growth that was surrounding Makena's neck. We were impressed with the possibilities and decided that Makena would come back to New York in January 2015 for five weeks to participate in the first phase of the clinical trial which would require both radiation of nodes on the back of Makena's neck and a new chemotherapy regimen.

The neck tumors required twice daily dressing changes.

And Dr. Makena continued to see patients, and no one ever knew.

2015 (Neck Tumors, China, Oxygen, 71 lbs., Feeding Tube, Intubation, BIPAPs and Ventilators...)

Makena travels to Manhattan New York in January 2015 for five weeks and lands the day before the forecasted "Storm of the Century", she has travelled all by herself.

Makena books into a hotel room for the five week stay and settles in. Makena shops at Macy's and buys supplies that she will need.

I am on Jury Duty in Santa Ana, CA. I arrive at 5am and sit outside the Courthouse doors and order supplies on the new Prime Amazon.com while the local homeless ask me for financial assistance. The new Prime Amazon.com is the only access to delivery to Makena's hotel room in Manhattan. Makena consults with her patients over the telephone, and no patient ever knew.

Makena participates in the clinical trial therapies of radiation and the new chemotherapy and comes home on Valentine's Day, February 14, 2015. Her neck is raw with radiation burns and the dressing changes become more elaborate.

We pack our bags and prepare for the three week trip to China that Makena has booked. We have two huge suitcases and two huge duffle bags full of the bandages and sterile fluids that will be needed for the twice daily bandage changes of the neck. People look at us strangely as Makena is so small, yet she requires so many large bags of supplies...and they think, for what???

We travelled all throughout China for three weeks, with seven internal flights. We visited Shanghai, Suzhou, the Terra Cotta Warriors in Xian, Beijing, The Great Wall, Tiananmen Square, and The Forbidden City, a five day river cruise down the Yangtze River, Mainland China, and Hong Kong. We had a great time.

Our last two nights of this trip were spent in Hong Kong. Makena started to have trouble breathing, and this in turn would set off more laryngeal spasms. When we checked in at Hong Kong Airport, the wonderful and compassionate attendants at Cathay Pacific Airlines took one look at Makena and immediately upgraded us to Business Class! Hallelujah! And Makena slept the entire way home on this 15 hour direct flight from Hong Kong to LAX. We landed at LAX on April 1, 2015.

Once home, Makena rested for another day and was then driven to USC for chemotherapy.

Makena also prepared for another visit to NYU and Sloan Kettering to investigate a second phase of the clinical trial that she had begun the previous January. The debilitating neck tumor growth had slowed somewhat and we attributed that to the first phase of the clinical trial that she had participated in last January. So Makena flew back to New York by herself for five days to see the doctors for a checkup and to finalize the plan.

Once Makena arrived home in late April, we prepared to send her back for three more weeks to New York to complete the second phase of the clinical trial.

The debilitating tumors on Makena's neck now began to grow again and it became very difficult for Makena to eat and swallow and to breathe. It was determined that the tumors were now effecting the nerves related to swallowing and breathing. Makena then spent two weeks at USC Norris Hospital while they investigated these new problems. When Makena checked out of the hospital, she now required direct oxygen 24hours/day and had to carry oxygen canisters with her wherever she would go.

As Makena could no longer eat and swallow correctly, her weight plummeted to 76 pounds. We then checked Makena back into USC for another two weeks and had a feeding tube installed. This feeding tube gave us the much needed time and ability to continue the fight.

Makena came home and continued to see patients. I would drive Makena to her office in the morning and we would take the elevator up to the second floor. I would set her up in her office and hide the oxygen canister under her desk. When she would consult with a patient, she would turn the oxygen off and hide the cord and mask. I would also hide a second oxygen canister in the room next door just in case she needed oxygen while consulting with a patient. And if so, she would excuse herself and go to this room next door and use the oxygen and then return to the patient when she felt better. I would also drive Makena to twice weekly lung and respiratory therapy treatment appointments and we continued the battle. And no one ever knew...

On Saturday August 15, 2015, Makena and I flew to the Mayo Clinic in Rochester, MN. We knew that we had to get back to the Mayo Clinic as we needed the expertise of a comprehensive and integrative medical team to diagnose and treat what was going on with Makena. This would be our only chance as things were becoming extremely challenging again.

When we flew out of LAX on Saturday August 15th, we realized that we had yet again, just made it out in the nick of time. We had made it on the plane before the window of time of Makena's ability to travel closed. This would be Makena's last plane flight...

After two days of tests on the following Tuesday and Wednesday, Mayo Doctors committed Makena to the Mayo Hospital at St. Mary's in Rochester MN.

Mayo Doctors had identified a large mass that had grown significantly in both her left and right lungs since May 2015. It was either cancer or some type of fungal infection. This was the cause of her inability to breath without direct oxygen, and her complete exhaustion and inability to walk.

The significant growth of the cancerous tumors around Makena's neck displayed like a collar and was gradually strangling her, shutting down the nerves, and making it impossible and painful to swallow, thus the feeding tube was inserted four weeks previously. In addition, the tumors and radiation burns on Makena's neck had ulcerated and were bleeding profusely.

Makena's platelet count was down to 18, a normal person's platelet count is between 150,000 and 400,000. This directly impacted her ability to stop bleeding, thus the significant bleeding from the ulcerated areas around her neck.

The existing tumor on her vocal cord coupled with the nerve damage from the ulcerated tumors around the neck have also further reduced Makena's ability to communicate and speak clearly.

The only way to determine whether the mass in the lung was cancer or fungal was to go in there and get a sample. This would require a choice between two very dangerous procedures, either a bronchoscopy, wherein they go down through the throat where Makena's airway was already compromised and the tissue was very tender from the tumors, or a CT guided insertion of a needle into the lung through the back or the chest to get the sample. Both options are normally simple and low risk procedures, but not in this case due to all of the medical challenges that were currently displaying at the same time.

The Mayo gave Makena platelets to get her platelet count up. This would require days to get to the level needed before they could do either procedure.

We would need to stay there in Rochester, MN, for at least one more week, maybe even two, to get through this.

The challenges continued as the sputum from Makena's lungs tested positive for Cancer. Now both the bronchoscopy and the biopsy procedures were cancelled.

Makena would become very agitated as all of these significant challenges started to pile up. She then had a very negative reaction to some medications that she was given to help with this agitation. In addition, Makena's CO₂ levels rose to over 100 (normal is between 35 and 45). This was a result of the inability of Makena's lungs to efficiently removing the CO₂ gases. This in turn, sent Makena into almost unconsciousness and completely loopy.

They rushed Makena to the Intensive Care Unit (ICU) and placed a breathing device called a BIPAP on her. This was a full face mask, like a diving mask device, that pushes air in and removes CO₂ gasses. Also during this period the doctors communicated that if the BIPAP did not work, then we would need to make a life or death decision, ventilator or no ventilator. And that the choice of a ventilator, would mean a very grueling and ultimate death while the cancer progressed.

Makena chose no ventilator. Makena also chose to not wear a DNR = DO NOT RESUSCITATE bracelet. Makena still wanted to fight and win and to not give in.

And the BIPAP worked! Makena was now able to rest in the ICU during the day without the BIPAP and would only need to wear it at night.

Now, the next order of business, was to deal with the new cancer finding, and the yet again reduced physical state of Makena. Painful lymphedema had set in on Makena's face and right arm.

Makena still wanted to fight on. The options were minimal. One of them was a clinical trial at MD Anderson in Houston. Going home to Orange County, CA, would mean definite death.

And a major problem was that Makena was in no condition to travel.

Our first goal was to get Makena strong enough to leave the hospital. Then fly her to MD Anderson in Houston, Texas. The challenge here was that a commercial airline may not let Makena board the plane due to her severely weakened condition, and she may not be able to travel the entire distance in a vehicle, I would therefore need to hire a private medical jet...

If we were able to get to MD Anderson in Houston, I would need to get things set up there, and hire support services like I did four years ago. Ultimately, we were looking to get Makena into the clinical Trial at MD Anderson for ONT-380. Promising clinical trial results had been presented at the American Society for Clinical Oncology (ASCO) Annual Meeting in 2015 that showed activity of the investigational anti-cancer agent ONT-380 against HER2+ breast cancer. In one case specifically against brain metastases and in another case in the overall survival of heavily pretreated HER2+ breast cancer patients. This would have been a perfect fit for Makena's exact diagnosis.

And no one was in denial. At the end of the day, we knew that even if we did get to MD Anderson, the inevitable was the inevitable. When cancer grows at this rate it grows exponentially and displays as it is displaying right now. We were determined to fight on and not succumb any ground to this scourge of a disease called breast cancer.

Makena was then transferred to the Respiratory Therapy Unit (RTU) as the BIPAP was working and she was stable.

It was in the RTU that Mayo staff spoke with Makena and Makena reluctantly agreed to wear the DNR = DO NOT RESUSCITATE bracelet. Makena felt EXTREMELY uneasy about this...

Mayo staff would keep Makena under a 24 hour watch and place a nurse by her bedside. Makena would actively demand full physical therapy and walk with a walker around the hallways. Sometimes the BIPAP at night would not exhaust enough CO₂ gasses and I would wake to panicked text messages from Makena at 4am as she would text me stating that there were strangers in her room and ask me to get there quick. I would run across the street from my hotel room and into the RTU only to find that these "strangers" were either the nurses stationed bedside or the helium balloons that were in her room...

It was now Labor Day Weekend. I asked the doctor's if it was safe for me to fly back to California for a couple days to handle some personal and business items that needed to be addressed. The doctors said that Makena was stable, so I flew out on that Saturday night. I checked in with Makena and the doctors multiple times the next day, Sunday, and they all informed me that all was well. On the following Monday morning, Labor Day, the doctors informed me that the BIPAP was no longer working and that Makena was no longer stable. I immediately booked a flight that same day and flew back to Rochester, MN.

When I arrived that Monday Labor Day evening, Makena was loopy as the BIPAP was no longer exhausting the CO₂ gasses. The next morning, Tuesday morning, Makena was completely unconscious and the decision was made to perform an emergency tracheotomy as that was the only way to allow the CO₂ gasses to exhaust without being permanently intubated and placed on a ventilator.

Once in the Operating Room, Makena was intubated to ensure a solid airway for ventilation. While the ENT Surgeons were preparing Makena's neck for the tracheotomy they noticed that the tumor had completely enveloped Makena's neck as the site they were injecting was not absorbing the anesthetic. The ENT's then cancelled the surgery and informed us that it was too dangerous to proceed.

When Makena regained consciousness, she was now intubated and on a ventilator. The intubation solved the issue of the removal of the CO₂ gasses, however Makena would now spend the rest of her remaining days intubated and on a ventilator. A very, very uncomfortable experience...

In fact, this is why critical care ICU patients are asked to decide whether or not they choose to wear a DNR = DO NOT RESUSCITATE bracelet. If they do not, then the doctors must do everything possible to resuscitate the patient if they become unconscious, and this includes intubation and the installation of a ventilator for the remaining days/weeks of life. An extremely uncomfortable experience and way to live in one's final days.

And now, here we were once again. Makena's fierce determinism to live and beat this cancer resulted in a situation where a patient, i.e. Makena, was intubated even while wearing a DNR bracelet!...

Makena then chose to remove the DNR bracelet from her wrist and I supported that decision. This was Makena's way of communicating that she will accept nothing less than a tracheotomy and she is willing to keep the intubation tube in and gag until the doctors concur. God bless this woman!

The best possible outcome would be to either get the green light for an immediate tracheotomy or the green light that they were open to performing one.

The alternative WOULD BE GRUELING for everyone. A decision to pull the intubation tube would mean watching Makena start to twitch again and get loopy again as the CO₂ gases would build up. And the morphine would be increased to reduce Makena's anxiety and put her into an eventual and final sleep. This would absolutely be the most horrific and worst possible outcome that we could ever have.

And it would include not only removing all HOPE from Makena but absolutely crushing this HOPE when she is in a completely weakened and helpless state with a tube down her mouth, gagging, and unable to speak.

Makena was a HUGE light of a human being, and we would be absolutely crushing and stamping out this light.

And I think we all knew that the best possible outcome of being able to get to the tracheotomy surgery would be to watch Makena go to sleep with HOPE while they prepare her for surgery, a surgery that she will very probably not survive and never wake up from. And if she did wake up, it would be a miracle and "God's will" and we would take it from there.

On Friday 9-11-2015 after a 4 hour very intense conversation regarding the installation of a tracheotomy, Mayo ENT staff state that they will not perform the surgery as it is not possible with existing tumor growth. There was an EXTREME danger of cutting the carotid arteries as they were surrounded by tumor and pieces of tumor would continue to flake and fall into the lung after the surgery and continue to cause infection.

We had pushed for four hours. One doctor became so frustrated at Makena's unwillingness to "give in" that he had to leave the room to regain his composure.

We were then scheduled to consult with three other ENTs over the next week whom may have the expertise to do the extremely complicated surgery. We would not stop looking. In the interim Makena laid there intubated and unable to speak. Close to inhumane. Makena would need to be medicated every 30 minutes for anxiety and then put to sleep when the anxiety became too bad.

At the end of the day, this landed as a true testimony to the fact that Makena had exhausted just about every possible treatment that could be performed to stay alive.

On a side note, it was comforting to see the amazement of the brilliant Mayo MD minds as they realized what we have done over the past 9-10 years to stay alive and continue to beat the cancer.

At one point the whole room filled with eleven Mayo M.D.'s, Surgeon's, ENT's, and Oncologists was in tears of frustration after Makena scribbled in micro writing on her communication pad "1 Corinthians 13:1" "If I speak in the tongues of men and of angels, but have not love, I am only a resounding gong or a clanging cymbal"...

This was such a horrific thing happening to such a light in life.

There were really no good options remaining.

Option #1. Remove intubation tube and the ventilator, up the morphine, go to sleep forever.

Option #2. Live as long as one can in this current horrific state of anxiety while intubated with the breathing tube, gagging and unable to speak.

Option #3. Find an ENT with the expertise that will chance the surgery.

On Saturday 9-12-2015 we spoke to another ENT. A brilliant one that wreaked intelligence and capability. Whereas he strongly recommended against it, the tracheotomy option was now back on table. The concern was that the tumor laden area would never heal properly and would progressively get worse as the trachea would rub on it. And eventually as the tumor tissue would deteriorate the carotids would rupture. This brilliant ENT gave the best case scenario of 7-8 weeks to rupture and a bloody death.

Other options would be to keep the existing breathing tube inserted or change it out for one that would be inserted through the nose. These were the safest options. They also stated that all options would require Makena to be forever connected to a ventilator, and that Makena would never be able to leave the ICU, except perhaps to go outside and see the sun. Eventually, either carotid artery rupture or cancer or pneumonia or infection would take her out. And we were not sure we agreed with all of this. There were still many unanswered questions that we were pursuing answers to.

Our plan was to complete the interview/decision making process, and decide on the path forward. Makena was very probably going to choose the tracheotomy as she did not believe that her carotids were going to rupture so quickly and this choice would give her the most quality of her remaining life.

I knew that there was going to be a pause in the room when they asked Makena and she would write her answer... If Makena did choose the tracheotomy the surgery would be ASAP. And in a perfect world, I would be able to dig in and be there, by her side.

Every day was an intense day of fact finding, processing and decision making. And a clear necessity to determine what the facts really were. Just because someone says something, does not make that something a fact. And when someone says something, and others then repeat it over and over, it somehow takes on a life of its own as a “fact”. And in reality, if you trace this “fact” back to its beginning, it was conjecture, not a “fact”.

And now it is being treated like “fact”, and it must be identified for what it started as, i.e. someone’s conjecture...Not a “fact”!

Makena’s left lung now required daily bronchoscopies to pick out mucous pieces and other debris as a result of the cancer that surrounded and was inside the left lung. And these bronchoscopies were performed through the intubation tube.

We had decided to stop pushing for the tracheotomy and instead inquire into whether or not a larger breathing tube could be installed that would allow for bigger tools to be used to pick out the debris in the left lung. Remembering that the existing breathing tube was installed during a planned tracheotomy, and would have been removed after the tracheotomy, perhaps they may have been able to install a larger breathing tube if they had known that this tube would now be permanent. All in all, the left lung was blocked, with an infection behind the blockage, and the existing bronchoscopy tools were not big enough to get through the debris. A larger breathing tube would mean bigger pickers and tools would be available to remove the debris in the left lung.

So Makena’s left lung had shut down from the cancer and she was left with one right lung that only worked to 65% capacity, and therefore required a 24hr/day connection to a ventilation machine.

Sadly, now the only possible remaining goal may be a palliative one, and the worst part was that Makena, God bless her, hated that word, “palliative”...

Makena lied intubated and on a ventilator in the ICU. She could only communicate with hand signals and writing on a pad.

Makena was soooo very brave. Such an amazing 76 pound piece of fight and determination. She often wretched with the tube down the throat, and then would go on with her fight and determination.

Nothing short of AMAZING...

We now would no longer be investigating the replacement of the existing intubation breathing tube for a larger one as the high risk of replacing the existing breathing tube for a larger one was not worth the benefit.

Makena had a solid airway with the existing breathing tube, and the replacement process would include a time period with no guaranteed airway, and if things went south, they would go catastrophically south.

So here we were, we had one last confrontation with oncology to get one more round of chemotherapy in the hopes that this would slow the cancer and possibly lead to a recovery path.

There was always hope.

Oncology said that Makena was too weak to handle a dosage of chemotherapy and that it would very probably have the opposite effect, and would shorten her life, and/or kill her.

We maintained that this was simply a “judgement call” as Oncology does not know for sure that the chemotherapy dosage will shorten Makena’s life.

All we did know for sure was that the cancer if left unchecked would in fact take her life.

And therefore, in our opinion, Makena, as a physician and surgeon and philanthropist that has helped thousands of people during her 56 year short and very bright light of a life had earned the right to freely choose. And therefore deserves the “nod”.

Makena knew the consequences of her decision, she was still as sharp as a tack mentally. While Makena would fade in and out of the Morphine and the Fentanyl for agitation, and the Propofol for sleep, she would graciously write on her paper pad “Thank You” and write bible verses from memory. She brought the eleven M.D.’s to tears the other day, while all in one room when we were battling for the tracheotomy, and Makena clearly wrote on her communication pad, 1 Corinthians 13:1 “If I speak in the tongues of men and of angels, but have not love, I am only a resounding gong or a clanging cymbal”.

We did ultimately win the tracheotomy conversation and they did put that option back on the table. We simply chose not to take it as we had determined that the benefit of that window had closed already.

Interestingly enough, Mayo’s issue was that they were afraid of eventual rupture of the carotid arteries, in 5-7 weeks, which would be a very messy and bloody death. And upon hearing this, Makena wrote, “I know, I have been in the OR (Operating Room) when someone nicked the carotid artery, I am completely aware of the risks”...

September 15, 2015

I would write notes at 4am to clear my mind and get ready for the intensity of the new day.

Today was September 15, and we had flown out of LAX on August 15. An entire month had rolled into another broad swath of a most memorable, sometimes joyous, and intensely grueling time of life.

We would adopt the philosophy of the 23rd White House Chief of Staff, Rahm Emanuel, the philosophy of “Win the Day”, and focus all of our efforts on doing everything necessary to “Win the Day”.

An Oncologist by the name of Dr. Bancks came by in the early morning to discuss the case with the family.

The Mayo Oncologist’s and Dr. Tripathy’s argument for no more chemotherapy, was that Makena has had many years of chemotherapy over this nine year battle. And there comes a point where more chemotherapy may do more harm than good. And they knew that they had already crossed that threshold with Makena and may have actually harmed her. In addition Makena’s functional status was very low as she was very weak, she had been intubated with a breathing tube, and required a 24 hour connection to a ventilator. And even though her platelet counts were now back up to 103 the day before, they could not deliver chemotherapy to such a very weak and low functioning patient on a ventilator in the Intensive Care Unit of the Hospital.

Our argument for more chemotherapy and or treatment was as follows:

1. Makena had been an outlier over the past ten years with her breast cancer battle. And she was still alive because of this. Makena was very smart and would seek out very smart people for care and support and advice and friendship, Makena was a very aggressive fighter that would never give in, and we have had the finances to pursue whatever needed to be done, wherever and whenever it needed to be done, and we have had an amazing medical insurance coverage through the company that I work for. And because of this, Makena was still alive as we have left no stone unturned.
2. Makena was also a very accomplished physician. After 5 years of medical school, she actually chose to repeat one year in her pursuit of excellence after being told that "she would never make it". Makena then did a 5 year trauma/surgery residency at UMDMJ in Newark NJ, working 120 hours per week before the laws were drastically changed to make it illegal to work doctors in training that many hours especially in hospitals in downtown Newark NJ where the violence is extreme. She then did a two year hand and micro surgery residency at USC and a two year plastic surgery residency at UCI, and trained for another year with the man that invented tumescent liposuction, Dr. Jeffrey Klein. You may remember the 60 Minute special on Dr. Klein in the 1990's.

AND WHO BETTER CAN KNOW THEIR OWN BODY AND HOW IT REACTS HAVING LIVED IN IT OVER THE PAST NINE YEARS OF AGGRESSIVE METASTATIC CANCER TREATMENT THAN THIS TRAINED PHYSICIAN HERSELF.

3. Makena had also been HUGE in the world of philanthropy. Every year, during Makena's 5 year trauma surgical residency at UMDMJ in Newark, NJ, and for some time afterwards, Makena would team with her friend, Victoria Waldock, and would raise all of the funds and coordinate all of the surgeons and medical supplies and air flights to fly surgical teams to various countries in Africa. Makena would speak directly with Sir Richard Branson and ask that he donate the airline tickets on Virgin Atlantic and these surgical teams would train African hospitals and surgeons and surgery centers in the modern ways of pediatric surgery and cleft lip and cleft palette and other deformation repair surgeries. They would coordinate and host dinners and other events at the United Nations with foreign dignitaries, and US Senators, and movie stars giving their support and attendance. Audrey Hepburn, Lionel Richie, Richard Branson, Dick Gregory, the names go on and on and on. Makena was invited to sit next to First Lady Nancy Reagan and President Ronald Reagan the first day that President Reagan appeared again in public, in church, after he was shot in the assassination attempt in 1981. Audrey Hepburn would invite Makena for tea in her Manhattan NY apartment. And Makena would continue this philanthropy with our 501(c)(3) non-profit "AnswerAfrica". We had formed AnswerAfrica in 2006 and have raised over \$1.3Million, delivered over \$600K in medical supplies and equipment, and provided over 200,000 mosquito nets to rural and remote areas and villages in Kenya. Having never taken a single cent for herself, not even for the air flights or food or hotel or gasoline or anything required to get this done. 100% of ALL monies went to the mosquito nets and medical supplies.
4. The Oncologists **DO NOT KNOW** for sure, and will never know for sure, whether or not more chemotherapy will prolong or reduce Makena's life. Especially since medicine is a judgement call and not an exact science.
5. What we **DO KNOW** for sure, is that this cancer, if left unchecked, **WILL KILL** Makena.

6. Given all of the above, if a person such as Makena described above does not deserve the “nod” for more chemotherapy, when “nods” and judgements are given all the time in medicine, to people far less intelligent and responsible in all of their actions and in the knowledge of the potential downside of such actions, then I do not know who does...

And amazingly enough, the Oncologist Dr. Bancks, said that she would pursue the chemotherapy conversation with her team and also contact Radiation Oncology to see what if anything they may be able to contribute!!!!

And the miracles continued!

Three hours later, a Radiation Oncologist showed up at Makena’s bedside, and agreed to investigate what could be done to provide further radiation to Makena’s neck. Radiation to the tumors that had now paralyzed both of Makena’s vocal cords. This vocal cord paralysis was the reason that Makena could not exhaust her CO₂ gases, and was one reason that Makena was still hooked up to the ventilator. AND he would investigate radiating the lymph nodes that were causing the pressure on Makena’s left lung that had closed off the entry of air into two lobes of that lung, lobe 1 and lobe 2. These blockages had basically shut the left lung down and enabled an infection to grow that we could not get to in order to clean out.

And this Radiation Oncologist, Robert Mutter M.D., knew Dr. Buchholz at MD Anderson!!! Having interviewed at MD Anderson with Dr. Buchholz and having gone to dinner with Dr. Buchholz and his wife!!! Hallelujah!

Dr. Mutter immediately went into gear and contacted MD Anderson to get Makena’s radiation records and speak with Dr. Buchholz!

September 16, 2015

We heard back from the oncologists and they had agreed to give Makena another round of chemotherapy after she completed her antibiotics for the pneumonia on September 19. They stated that there was only a small chance that it would help her and a much larger chance that it would hurt her. But Makena wanted it so they gave Makena the option. Makena got the “nod”... In addition, we were still waiting to hear back from Radiology on whether or not they could address the cancer lymph nodes with radiation as that would be the fastest way to possibly open the left lung back up.

We were completely aware that we had now crossed the line from leaving “NO STONE UNTURNED” to “LEAVING NO GRAIN OF SAND UNTURNED”. We would not let this bright light of a life fade or go out without dissecting each piece of sand.

And believe it or not, Makena was in great spirits, and loved the thrill of the fight!

Makena’s friends would call her and we would hold the phone to her ear while she listened and smiled and then Makena would write instructions on her pad. Makena still had her amazing ability to get teams of people working on what needed to be done.

Makena would get anxious at times, understandably, and nurses would just increase the Fentanyl or the Morphine or the Propofol when that would happen. And then Makena would calm down, and go to sleep, and then she would wake up and we would start all over again to WIN ANOTHER DAY!

September 17, 2015

I sent the following email to both Radiation Oncologist's, i.e. Dr. Buchholz and Dr. Mutter:

Please read trailing emails so that you can better understand the background behind Makena and her family's request to do everything possible to provide more time with her life.

Makena is asking for the permission to make her own choice, as that is how she defines Quality of Life.

And Makena chooses to take the chance, as it is in the end, a judgement call based on past experience.

The only guarantee is that this cancer, if left unchecked, will kill her.

Additional radiation to any node that is contributing to the closure of the left lung may harm her, may do nothing, and may do something.

No one will ever know for sure.

We do know however, that doing nothing and leaving this cancer unchecked will kill her.

Please have an open and candid conversation after reviewing this entire email string.

And THANK YOU for who you have been for my wife during this fight with cancer and for who you both are in the world.

Most Sincerely,

Craig

September 18, 2015

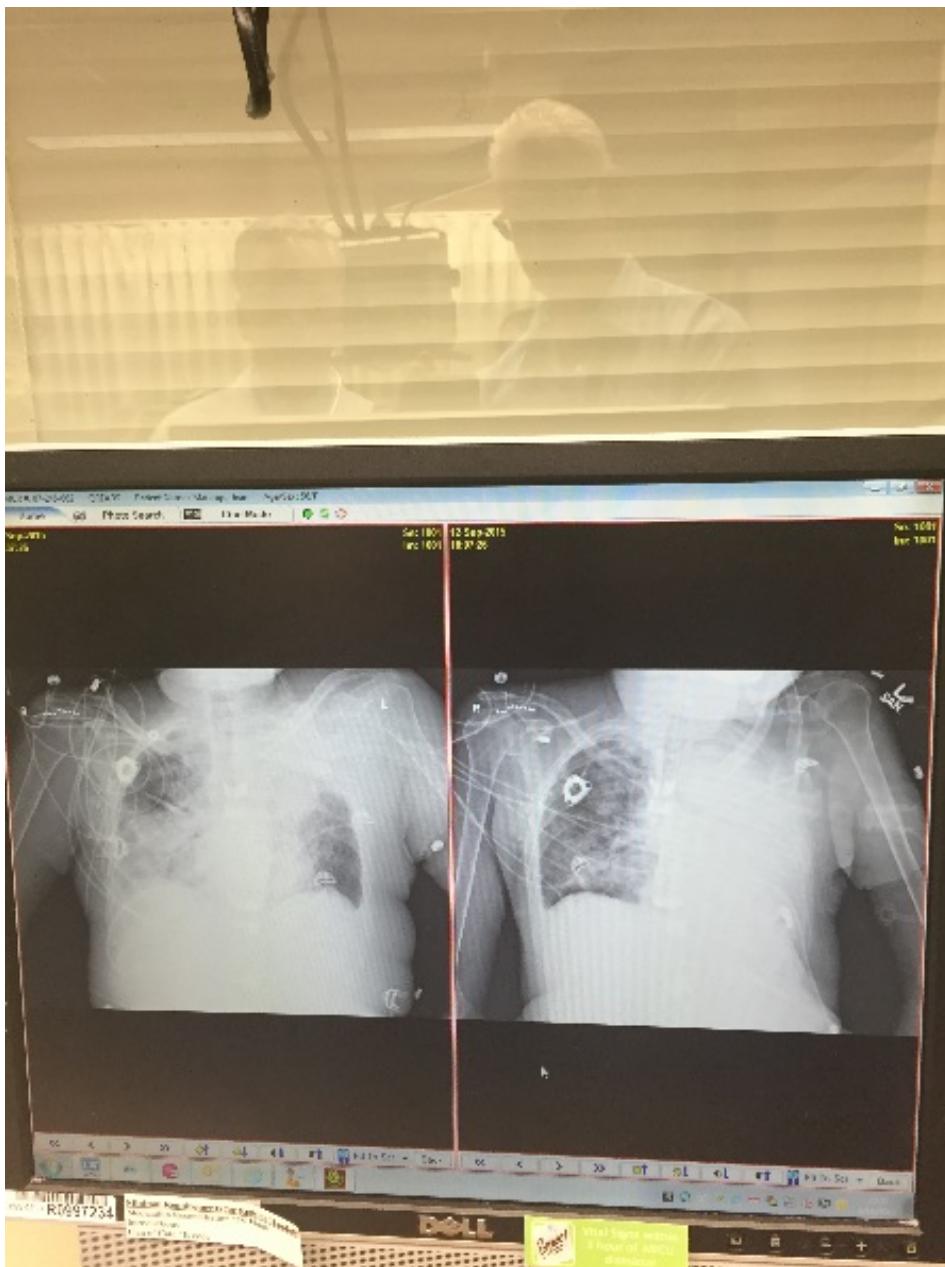
I sent the following email on the evening of September 18, 2015.

I wanted to give everyone an update. Please read trailing emails for history.

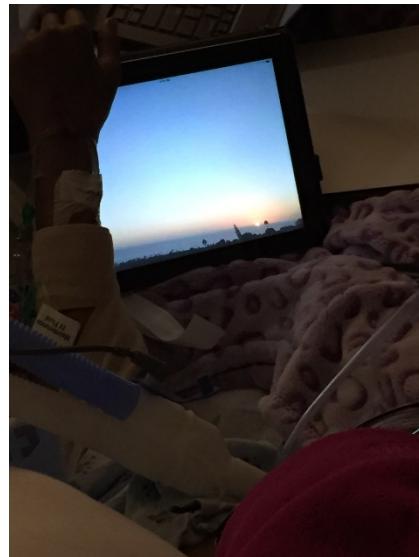
Sitting here with Makena watching her sleep and playing our FAVORITE soundtrack!

Pictures attached.

1. We started the day with a chest XRAY that showed that the left lung was working again! However the right lung now had pneumonia. See attached XRAY picture. XRAY on right taken on 9/12 shows complete blockage of Makena's left lung. XRAY on left taken today 9/18 shows some opening of left lung and much pneumonia in right lung even though Makena has been on strong antibiotics. They will increase antibiotics to address the pneumonia.



2. The Oncologists are still willing to deliver chemotherapy after the pneumonia is resolved.
So that is good news!
3. Makena wanted me to convey how much she LOVES everyone.
4. Makena LOVES the sunsets over the Pacific Ocean from our back yard in San Clemente. A few years ago I trained one of the security cameras on the Ocean View so that she can see it wherever she is in the world! Please see attached pictures "Makena Watching Sunset from Home" and "Makena Holding Sunset from Home". Makena fell asleep tonight at peace holding on to her sunset.



5. And the best part of all this is we are listening to some of Makena's most favorite songs, Meatloaf's "Two Out Of Three Ain't Bad" Lee Ann Womack's "I Hope You Dance", Greg Holden's "The Lost Boy", and John Lennon's "Imagine".
6. Makena sleeps very peacefully tonight. At peace with the world and resting to "**Win another Day**"!

September 19, 2015

Makena finished the pneumonia medications but the pneumonia had sadly progressed. The Doctors continued with another round of pneumonia medications. Makena simply rested and slept most of the day as the next step was to wait until the second round of pneumonia medications were complete and then get the promised round of chemotherapy that we had battled so hard to get the approval for.

September 20, 2015

Makena continues to rest and sleep as we all pray that the second round of pneumonia medications will clear the pneumonia. I am eating dinner at a restaurant close by and I get a phone call from the nurses informing me that Makena's life functions are shutting down. I run the $\frac{1}{2}$ mile back to Makena's bedside and hold her hand and tell her "I Love You" while a chaplain prays with us and as Makena passes away at 7:43pm Pacific time.

September 21, 2015

I sent the following email on Monday September 21, 2015 @ 5:51 AM

Makena passed into the arms of the Lord yesterday evening at 7:43pm Pacific time on 9-20-2015.
I have no doubt where Makena is and the fact that we will spend eternity together.

And it just so happened that this was during the Emmy Awards. So it looks like God got an Emmy yesterday...
The brightest and shiniest one of them all!!! My Makena...

The attached pictures of yesterday's sunset of 9-20-2015 were taken by Makena's dear friend and neighbor, Alba Dehli. Alba and Makena used to go walking in the hills above San Clemente with the ocean views and breezes. Alba was one of Makena's dearest friends. Alba lives with her husband Hans in the house just above and South East of ours in San Clemente, CA. These pictures show the view from just above and over our house and they include the palm trees in our front yard that Makena loved sooooo much.

As Makena passed at 7:43pm Pacific time on September 20, 2015, this was the time of this sunset, and we can see this bright beautiful light as it rests for the day behind Catalina.

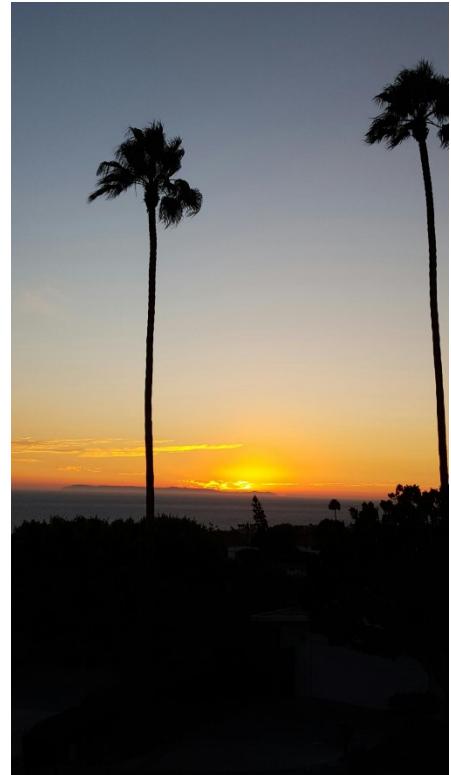
This was Makena's sunset.

And I know that this was Makena being laid to rest and being greeted by the Lord. And the Lord said "well done my good and faithful servant, enter into the kingdom prepared for you since the beginning of time".

If you receive this email, whether directly or indirectly, please know that you were very special to Makena.

And Makena would want you to know that she LOVES YOU and wishes you all of the brightest in this world.

Love Makena and Craig



Afterward

Very few people knew that my wife, Jean Ann Makena Marangu., M.D., had been battling Stage IV Metastatic Breast Cancer since 2006. Makena was a very private person.

Makena was also a very accomplished physician. After 5 years of medical school, she actually chose to repeat 1 year in her pursuit of excellence after being told that "she would never make it". Makena then completed a 5 year trauma/surgery residency at UMDMJ In Newark NJ, working 120 hours per week before the laws were drastically changed to make it illegal to work doctors in training that many hours especially in hospitals in downtown Newark NJ where the violence is extreme. Makena then completed a two year hand and micro surgery residency at USC, a two year plastic surgery residency at UCI, and trained for another year with the man that invented tumescent liposuction, Dr. Jeffrey Klein, you may remember the 60 Minute special on Dr. Klein in the 1990's.

And along the way, Makena experienced some horrific acts of racism that no human being should ever have to experience. And yet she continued on, and was never the victim. I will always remember her telling me when I was quick to temper, "Craig, they are doing the best that they can with what they have, be the bigger person, and give them grace".

Makena knew the consequences of all of her decisions. Makena was as sharp as a tack mentally until the very end.

And in the end, my wife, Makena, was faced with some extremely tough choices, and in her usual "mongoose on a cobra" fashion, chose to aggressively attack her cancer until her body simply gave out.

In the final days, Makena was fed through a feeding tube, and was intubated with a breathing tube, unable to speak, on a ventilator, and communicating via written word in between the blur of Morphine for pain, Fentanyl for the agitation caused by oxygen starvation, and Propofol for when they had to knock her out. And in that fog, Makena would assemble a room of 11 Mayo Clinic MD's, Oncologists and ENTs and Radiologists, and bring them all to tears when we were battling for a tracheotomy, more chemotherapy, and more radiation, and then Makena clearly wrote on her communication pad, "**1 Corinthians 13:1**" "**If I speak in the tongues of men and of angels, but have not love, I am only a resounding gong or a clanging cymbal**".

Makena chose to kill cancer cells on her way out knowing that the treatment to continue to kill those cells also had a 99.9% chance of killing herself. And the win was in taking another dead cancer cell with her.

Some were privy to the "blow by blow" over these final five weeks and over the past ten years, most had no idea, as that is how Makena liked to fight her fight.

And it is with the utmost of profound respect that I have for my amazing wife of sixteen years, that I have assembled this booklet on Makena's final journey. And I would like to share her passing with her friends and acquaintances via this booklet.

Makena's amazing life of accomplishment, philanthropy, and aggressive "mongoose on a cobra" fight and spirit, is as impressive as they come.

During this final 5 years of the 10 year fight, Makena also decided to travel even more. To see more of the world and celebrate the life that she had left.

Makena travelled to:

1. California. Three Rivers, Sequoias, Yosemite, Napa Valley, Sonoma Valley, Northern CA Redwoods all the way to the Oregon border.
2. The Caribbean, Aruba, Bonaire, Curacao, and the Bahamas.
3. Costa Rica, Panama and the Panama Canal.
4. Back to Kenya, for another safari.
5. USA, Grand Canyon, Sedona, and Scottsdale AZ.
6. South America, Argentina, Uruguay, and Chile, and rounded the violent and turbulent waters of Cape Horn where the Pacific Ocean meets the Atlantic Ocean on a Holland America Cruise ship.
7. Tahiti, French Polynesia, Bora Bora, Rora Tonga, Aitutaki and the Cook Islands on the Paul Gauguin Cruise Ship.
8. Thailand, Cambodia, Vietnam, and Laos with friends.
9. Brazil, Rio de Janeiro and Ipanema and Copacabana Beaches, Sugarloaf Mountain, Christ the Redeemer, and both the Argentinian side and the Brazilian side of the Iguazu Falls.
10. Peru and Machu Picchu, as you now know on her own.
11. Europe, Prague, Budapest, Germany, Austria, Holland, Russia, the Viking River Cruise of the Rhine, Main and Danube Rivers.
12. And we travelled to China in March of this year for three weeks, seven internal flights, we went all over China, Shanghai, the Terra Cotta Warriors in Xian, Beijing, The Great Wall, Tiananmen Square, The Forbidden City, a five day river cruise down the Yangtze River, Mainland China, Hong Kong.

Makena was a fighter and an adventurer!

And as Makena would say... "Carpe Diem"











