

To Whom It May Concern:

Something needs to change. Every day, seemingly healthy and vibrant kids across the U.S. and the world are diagnosed with cancer. Most of these kids had no known conditions or genetic mutations that led to this disease. It was just an unlucky draw that started a process that they could not stop themselves. They did nothing wrong. The parents did nothing wrong. It is something that could happen to any child at any time. There is currently not a haven, preventative measure or routine approved test that can help lessen the impact of or prevent this disease.

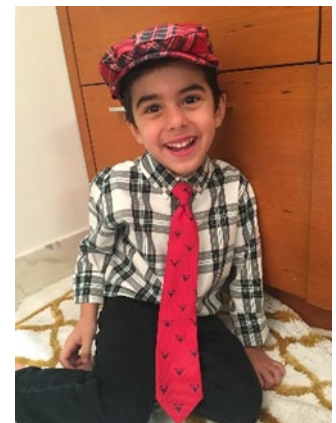


Our beautiful son, Santiago, at the young age of 4 years old was diagnosed with an aggressive form of Brain Cancer called Medulloblastoma. After a 4-year very difficult battle, he is now gone. He will never experience his first kiss, hit a home room, graduate from any grade, go to prom, find the love of his life, experience the joy of having kids of his own and experience all the countless other joys life has to offer. His life was robbed from him.



The worst part of this story it did not have to be this way. There was a cure for his disease with the technology that existed then and today that would not have caused as much damage to his young body. There were tests that were not performed, precautions not taken and treatments given without regard to safety. This is what is today called the "Standard of Care".

While there is very little we can do today to prevent this disease in children, there are ways we can test, treat and cure this disease without the harmful long term side effects. There are potentially life-saving tests that can and should be done upon diagnosis that are not done due to costs and the lack of insurance coverage for these tests.



When Santiago was first diagnosed, we went along the recommended path of standard of care including surgical resection of the tumor, chemo and radiation. We had no time to research and see the viable options. We were told there was one path and we had to go down it or our son would die. This was not true.



Unfortunately, half-way through the treatment, Santiago developed severe radiation brain stem necrosis from the proton beam treatments which lead to paralysis from the eyes down. Almost every kid that receives this treatment for Medulloblastoma is significantly impaired cognitively and with some physical damage.

We were never told that our son could experience this type of side effect or there was anything we could do to reduce the chance of the permanent side effects.

All we had left after his paralysis was one good eye (which he could communicate yes and no) and his ability to smile and cry. He could not speak, walk, eat, breathe on his own or move his limbs voluntarily. However, we were told that his was cognitively all there but just trapped in his body. His beautiful and loving smile coupled with our unconditional love was more than enough to fight for his life and find a way to give him the best life possible.



We spent 8 months in the ICU where his heart actually stopped for a brief amount of time. Eventually, we were able to get out of the ICU and into a rehab center in Chicago. We returned home to Florida with our son barely able to move.

As we were not able to finish front line curative treatment of his brain cancer due to the paralysis, his cancer came back. In the next two years, we searched the entire planet for a cure or treatment that our son could tolerate without any harmful side effects given his fragile pulmonary and overall condition.

We tried to apply for almost every clinical trial but because of his paralysis, no trial would take him. The very medical system that caused the damage through harsh treatments, turned their backs on our son.

We were left nowhere. Our hearts sank but our resolve did not. We called every known doctor conducting trials on children and finally, we were able to get our son on an immunotherapy called Idoximod under an IND. Meanwhile, we did our best to enjoy life (going to Disney World almost every week as we moved to Orlando for treatments) and give our son a quality of life with the little he had. The immune therapy held off the cancer for some time but as recurrent medulloblastoma almost always does, it kept



coming back. It was clear that if we did not do something, our son would have no chance.

As harsh chemo was not an option, we again turned our search to the least harmful way to treat our son.

This is where we started to discover that there were many options out there to potentially cure our son but the scientists lacked the resources or the backing to develop them for use for kids. We discovered that important tests that could customize a targeted treatment for our son existed and were never even presented to us as even an option.

What I realized (and I am sure I am not the first), that the way childhood cancer and adult cancer is being treated is severely flawed. There really has not been major changes in the core treatment of cancer for over 30 years. Of course, there have been advances in the current modalities but the overall harmful construct of chemo, radiation and resection has not changed.

There is another paradigm that can work and has very little side effects - the use of standardized “personalized” medicine utilizing the latest genomic screening and other advanced testing along with personalized treatments and immune therapies. I know that a new model for treating cancer can be built from the ground up with the technology that currently exists and is being developed. The medical industry perhaps sees this but it is very limited due to regulatory and economic reasons.

Innovation in this space will likely need to be developed outside the system that is protecting the current way it works. I have lived passionately the last 4 years with the motivation of my son to figure this out. I am not a scientist but have the mental capacity to understand the technologies and how a new paradigm can be implemented. In fact, almost all doctors today recognize the limitations of the system but have little resources or motivation to change this. For the few mavericks that are willing to customize treatments outside the clinical trial setting, their work is often overlooked due to the lack of standardized data and is not even shared.

The system has to change for our society to move past this global pandemic of cancer faster. First, there needs to be a platform of sharing data of the innovative doctors using new treatment combinations. With a collective and standardized collaboration of individual success and failures, valuable insight can be drawn.

There needs to be a radical shift to personalized treatment of cancer based on latest sequencing (RNA and DNA) technology, morpho-proteomics, live tumor testing and AI. We need to move past the “McDonald’s” way of standard pre-made meals to a more customized approach. Large bucket classifications were a major advance 40 years ago but now we need to take a giant step further with latest generation sequencing in EVERY case.



I believe every tumor (if possible) should have:

- RNA / DNA Sequencing
- Have morpho-proteomics
- Live tissue should be preserved in a fashion that it can be cryogenically frozen so that it can be revived and used in live testing in a drug assay and possible a customized mouse model.
- Development of a vaccine for every patient to be given along with treatment or as primary treatment itself. This can be done very efficiently, safely and fast with the current technology.

This should be done as early as possible in the process. It can also be done in a cost-efficient way with some scale. Most of the time, tumor samples are put in a paraffin block and the ability to test the tumor effectively is gone. Doing this as early as possible (e.g., upon first resection and not just after everything has failed), could make the difference in hundreds of millions of lives of those that have the disease and billions of people who are directly affected (family and friends). This shift in paradigm will need to be achieved outside the conventional system in a more thinktank environment with the brightest minds in this field.



New non-harmful treatments need to be given a priority and funding to develop them into viable options. Families need to have support and information so they can access these treatments. With focus and resources, we can make it that no child or family has to deal with what our Santiago had to endure.

There are few lives not affected by cancer in some way or another. There is a desperate need for change and if we can do anything to help spark this chance, I believe it is our obligation to make it happen.

Warmest,

A handwritten signature in blue ink, appearing to read 'Richard, Claudia and Santiago'.

Richard, Claudia and Santiago