

FUNTASIA SPEECH

The Wings of hope as we REACH for the CURE

I would like to thank every one for all your generosity shown here today. Your support enables our foundation to take another step forward.

Thank you to our President Craig Eaton; it is by your leadership that has led our foundation in its ability to move forward in such a positive and profound manner.

To my fellow board of directors Susan Eaton, David Brooks, Suzanne and Dan Caputo, your tireless efforts organizing events like this, the golf classic and others we are making such a large and important difference in all areas of research, education and in the lives of people with MHE.

I believe GOD puts people in our lives for a purpose; it is for us to figure out what that purpose is. I also believe when you have the chance to say thank you; you must Susan Eaton THANK YOU. The word FUNTASIA is PERFECT, you can feel the magic in this room just look at all the people here supporting us today. Your drive for perfection is the same as mine. Our minds act as one and we make such a great team.

Your friendship is near and dear to my heart. Your words are comforting to me at the worst of times. Just when you thought you have seen it all MHE likes to take another hit. You know these past few months have been very difficult and you are here too comfort me. The tumor growing in Robert's spine we know there are simply no good options to deal with this.

Your spirit is holding my hand and your support clears my mind, so once again I am able to face the uncertainly of the future head on. Robert is my son, but I know that you feel he is yours to and I feel the same about Vincent. Suzanne and Dan you know I feel the same about Bobby. We will do what has to be done to get our children though all that they must face together.

My husband Dean our love story continues this bond unbreakable and ever lasting. I am forever grateful to you for the support you given me all these years and the life we share together with our son Robert.

I can not believe it's been 10 years since my son implanted the seed in my mind and as importantly in my soul to REACH for the CURE. There is now an entire community of people from all walks of life united in this mission.

BOTTOM LINE! MAKE NO MISTAKE ABOUT IT!

NO CHILD SHOULD EVER NEED TO FACE THE DESTRUCTION MHE CAUSES. TOGETHER WE WILL NOT REST UNTIL ALL CHILDREN ARE FREE OF ALL THE DEVASTING AFFECTS OF THIS DISEASE.

This past November I sat in an out door café in the heart of Venice Italy, filled with fear and apprehension. I was in Venice to give a presentation at a scientific conference before a world wide stage of about 250 researchers. You were thousands of miles away, but at the same time Robert, you were right by my side as always. I began thinking and reflecting about the strength you have shown each and everyday of your life.

I sat watching the many birds flying amongst, what seemed like cotton cloud dreams on this clear blue day in the middle of St Marks square. These birds were flying with boundless energies.

I became over whelmed by what this represented and started to write. Once again my son you touched my mind and soul in ways no one will ever truly understand. I wrote you the poem Pure White Wings.

It's about broken wings, but more importantly it's about the wings of hope. How each and every one of us are the care takers of the future, each in our own special way. So someday all children with MHE will have the ability to fly with this same boundless energies.

Not simply fly like the pure white doves you are, moreover our children will soar like eagle's achieving all the cotton cloud dreams that all young people have and strive for. With every cell of my being I know these wings of hope will one day lead the way to the cure.

THANK YOU Robert for teaching me by example, how to live a life filled with the wings of hope, sprit, courage and drive to over come what seems to be completely impossible at times.

I would like to ask everyone when you have a chance to walk over to the research board and take a look at some of the research now being conducted. The costs of research are huge and it is getting more difficult for researchers to come up with these funds needed to move forward. FUNTASIA and events our foundation holds; we hope to relieve a small part of the burden.

Our foundation is continuing to work hand in hand with researchers organizing many new research projects.

Our foundation is now co-organizing two more international research conferences. Scientists are receiving tumors samples, blood samples and clinal information they need to move forward.

They are continuing their work with [mice](#) and [zebrafish](#) models as a way to study MHE. Research is being transferred from one laboratory to another around the world.

Together we fly in search of the cure and the future looks so much brighter then it ever has before.

I would like to take this opportunity to thank our [Scientific and Medical Advisory Board](#) and introduce three members who are here with us today. There are no words to express our foundation's appreciation to these individuals.

Our advisory board is 10 members strong and has collectively published an astonishing 925 research papers in the fields of bone development, biochemistry, genetics and so on.

It is with this wealth of collective knowledge, their leadership abilities, their years of dedication they have shown in the fields of scientific discovery and exploration, the endless hours they donate to our foundation, that we will one day see the accomplishment of our goal of the treatment for Multiple Hereditary Exostoses.

Researchers are people too, with real feelings just like you and me. I have seen these advisory board members eyes well up with tears, their voices cracking as we speak about MHE children and what they must now endure.

But I also see the promise, all the magic, the sparks of energy in their eyes, the excitement in these voices as they form all these new scientific ideas and begin to explore them. It takes my breath away to feel the electricity in the air as the most genius of minds in all the different areas of research around the world, have set there sights on freeing our children.

I would personally like to thank these individuals for presenting our foundation with opportunity after opportunity to be an active part of research. To be on the inside and watch these minds at work is simply amazing.

To the government officials here today, your push for more awareness and funding support for research is greatly appreciated! The basic scientific research being funded today is the future of tomorrow and needs continuing funding by our government.

Without further hesitation I would like to introduce the advisory board members here with us.

[Maurizio Pacifici, Ph.D.](#), is the Director and Professor of Orthopaedic Research, Jefferson University College of Medicine, Philadelphia, PA

I caught your ear Maurizio in 2005 and shortly thereafter you jumped right into the fight not only with the research now being conducted within your lab, but also collaborating with researchers from around the world. During our meetings I see all these scientific ideas in your mind coming to life like bursts of lightning forming in the heavens and starting to take strike from every direction.

Our first honoree of The REACH Research award. This award has been developed by our foundation to honor a researcher whose work has already had years of long term REACHing impact on the study of Multiple Hereditary Exostoses.

[Dominique Stickens, Ph.D.](#) is now a Senior Research Biologist at Merck & Co. You were one of only a small handful of researchers in the mid 1990's who took an interest in studying MHE. Dr. Stickens discovered the second of the two genes that causes MHE, EXT2 and went on to characterize it. You were able to create an EXT2 knock-out mouse that formed tumors as a way to study this disease. These genetically engineered mice you created have proven to be a valuable research tool and are used by many researchers for the further understanding and underlying causes of MHE.

Dr. Stickens will be co-organizing the third International MHE Research Conference along with Dr. Yu Yamaguchi our next award honoree and our foundation.

Having gotten to know Dr. Stickens as well as I have over the years the EXT 2 gene is simply his baby. 10 years of your life you passionately researched MHE. The scientific discoveries that you have made can not be overstated. When we have REACHED our goal of a treatment, we will look back upon our journey and know, without question, that our success was largely due to your first research discoveries, and the information that was gained by your devotion.

On behalf of the MHE Research Foundation and with enormous honor as your friend, we have the distinguished honor of having Vincent Eaton presenting you with the REACH RESEARCH AWARD. THANK YOU

Our next honoree [Yu Yamaguchi, M.D., Ph.D.](#) is Professor of Developmental Neurobiology, at The Burnham Institute, in La Jolla, CA.

The Humanitarian Scientific Achievement Award was developed by our foundation to honor not only research but also the researcher's humanitarian efforts on behalf of people who suffer from MHE.

Dr. Yamaguchi's research includes neurobiology, bone and cartilage in order to study this disease as a whole with all that this entails.

Although frequently ignored in the clinical front there are other medical issues that some people with MHE suffer from. Some MHE patients tend to have mental and muscular symptoms. Back in April of 2003 I contacted Dr. Yamaguchi, and as we spoke, I told him about the different symptoms that I had seen in people with MHE, and went on to illustrate reasons why I thought these symptoms had not been correlated to MHE before.

Moreover how can the growing field of researchers really think about one day coming up with a treatment, if they did not know all symptoms of this disease and the impact they are having as a whole. How do scientists answer the questions with only half the story before them?

Our children are falling though the cracks and this is having a huge impact on their futures. Together we needed to do something about this. Without hesitation I heard the seed of scientific exploration being planted in his mind and in his soul.

For more then one hundred years MHE was thought of as a bone disease, where by multiple tumors form and bone deformity occur. Both researchers and physicians are now thinking in a different light, thanks to so much effort given by this one man.

MHE is a multifaceted disorder and needs to be understood in this context.

As more of this research emerges both parents and physicians will be able to intervene much earlier and get the child suffering from these symptoms such as learning disabilities the educational and medical resources they need to help them over come these challenges.

Dr. Yamaguchi started his quest, his thirst for knowledge to further the understanding of MHE by creating an EXT1 conditional knockout mouse model as way to study individual sights such as the brain, muscle and bone. This research demonstrated that mutations in the EXT1 gene that cause MHE, influence not only bone but also the nervous system. These mice are now being studied in more then 20 labs around the world.

His work related to bone has recently discovered that knockout of EXT1 in stem cells that are destined to become bone and cartilage causes severe bone abnormalities. These findings have provided new insight and understanding to the reasons why some of the bone deformity could be occurring along with the tumor formation. And also why many MHE patients frequently associate a wide variety of symptoms.

These insights also suggest potential novel approaches that can be explored in order to make the dream of a treatment transform into a reality.

On behalf of the MHE Research Foundation and with great personal joy and satisfaction, we have the distinguished honor of having my son Robert Ziegler presenting you with the Humanitarian Scientific Achievement Award. THANK YOU

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