Nov 4, 2006

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Attending and giving a presentation about the MHE Research Foundation and MHE research at the Connective Tissue Oncology Society Conference CTOS Link was an experience I will not soon forget. I arrived in Venice Italy two days early and got the chance to see many of the land marks in Venice.
I stayed in a hotel just a two minute walk to St Mark's Square. This is really a picture perfect place. As I was walking though this wonderful and magical city, I had the people living with MHE very much on my mind and took as many pictures as I could to let all of you get the feeling of Venice and what I was experiencing. I hope you all enjoy the pictures.

Then it was time to get down to business, the reason I had traveled so far. The conference was very enlightening as I had the chance to learn so much more about Chondrosarcoma. I also had the chance to meet the many physicians that I had been in contact with but had not had the chance to meet in person. We each finally had the chance to put a face to our names. The many physicians I spoke with asked me to bring this very important message home to people living with MHE. While the chances are small about 1- 5% that an Exostosis / Osteochondroma will have malignant transformation to Chondrosarcoma, everyone with MHE needs to be checked every 12 to 18 months. This gives your doctor a good base line to care for you. He /she will be able to more easily see any changes that could occur and watch them closely to help you receive the best health care possible. Please read the article authored by Dr. David Donati and Dr. Luca Sangiorgi both of whom serve on the MHE Research Foundations Scientific and Medical Advisory Board. "What is Chondrosarcoma? How it's diagnosed & Treatment Guide" PDF Link

On a personal note, I took one mighty deep breath before I got up to give my presentation. All the time thinking of the people with MHE and knowing the job I needed to do. Well I did not skip a beat, once I started giving my presentation I never felt so comfortable in my life. My fear and apprehension was gone and I got right down to business. I felt the wings of hope; like a baby bird who first starts to fly and boy did I soar. My sprit was free to accomplish the job I traveled so far to do.

I meet with Dr. Junya Toguchida, President of CTOS who comes from Japan and he has offered to take the time to translate all the clinical information about MHE into Japanese. This will be put up on the foundations website. I was also asked by Dr. Toguchida if I would consider attending a meeting he is organizing next year in Japan and share my experience once again. The same goes for a meeting I have been asked to attend in Span.

I met with the families that are organizing an Italian organization for MHE / Olliers disease and the clinical information also is going to be translated into Italian and located on both websites.
Dr. Sangiorgi is such a considerate person, making sure we had the time we needed to spend together not only to go over some research related matters but he also sat with the families and translated for us. Dr. Sangiorgi was the program director for the conference. I know first hand just how busy he was. The families had the time together and shared our (((hearts))) and when you do this the language barriers simply melt away. I know the children in Italy are in very good and caring hands. I got the chance to slip away from the meeting and simply walk though Venice and speak with these families just one parent to another.

I have had the opportunity to work closely with Dr. Sangiorgi over this past year and he is simply a joy to work with. I made many more contacts by attending this conference that will help bring MHE Research forward in the area of Genotype – Phenotype research that is now being conducted by Dr. Sangiorgi and Dr. Wim Wuyts and the foundation. I also made new connections with researchers working on animal models used in MHE research. We will be in touch with them shortly.

In closing I want to truly express to everyone the wings of hope are truly being felt around the world. The Board of Directors was honored that our foundation was asked to present our work to all of the attendee's of the Connective Tissue Oncology Conference. This foundation remains committed to bringing awareness, education and MHE research, around the world and a better quality of life to all people affected by MHE.

My Very Best Regards
Sarah

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