

The Legacy: Tradition of Family Involvement

Making a Difference – Three Generations at a Time

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In 2001 Ruth and Jack were urgently searching for the reason behind their 40 year old son suffering from PAVMs and TIAs. They finally found their answer at an HHT center. The path to that answer included Ruth's sister's HHT diagnosis quickly followed by Ruth's diagnosis. Being armed with the knowledge provided by the HHT Foundation, Jack and Ruth set on a path to educate their three adult children and grandchildren and encourage them all to undergo HHT evaluation and testing.

Today, Jack McMahon and Ruth McMahon continue to champion HHT education and awareness within their family and the broader HHT community.

When faced with a genetic disorder like HHT, health planning - much like financial planning- is critical to managing the disease and an important lesson this family passes on to each generation. Recognizing the importance of education and information, Jack and Ruth were already members of the HHT Foundation prior to their son's diagnosis. Once faced with a diagnosis of HHT in the lives of their children and grandchildren; Jack and Ruth wanted a more active role in advancing treatment options, furthering HHT awareness and understanding the process toward a cure.

Since the first family member was diagnosed until today when several members have a confirmed HHT diagnosis, the McMahons have become more involved in serving the broader HHT community. The entire family is involved from Jack, a past member of the Board of Directors to Chandra, currently serving as a Board Director, to the youngest generation who has attended the past two youth conferences as part of the National Patient & Family Conferences with their family. Their granddaughter, Brenna, demonstrated her knowledge of this disorder that affects generations in her family with a presentation about HHT to her middle school. Each generation is fighting back against HHT and making an impact for their family and for yours!

Patient education is a large part of the HHT Family Health planning, along with going to a treatment Center at least once (optimally), and positioning yourself to be your own best health advocate by learning about any breaking news as it relates to HHT. We meet so many multi-generation families attending the national



and regional conferences, all invested in educating future generations about managing HHT! Your support makes it possible for The HHT Foundation to offer these resources to all HHT families.

As HHT families know, this disease impacts the entire family, not just those who carry one of the HHT genes. Not surprisingly, as we all want to "fix" or help and take care of those we love. Many times, it is a spouse, parent, sibling or child of someone living with the challenges of HHT who turn to the HHT Foundation, to contact, join, and arrange to attend conferences, or contribute their time and talents to the HHT community. This "family advocate" generally takes the initiative to share information about HHT and the HHT Foundation with family members in need. Jack originally contacted Sharon Williams to participate in Capitol Hill Day. Six Capitol Hill Days later, Jack and Ruth are still immersed in this push for legislative support for HHT!

Chandra McMahon shares "I am truly grateful to my father-in-law, Jack (who doesn't have HHT), for being our first family advocate. Our entire family has benefitted tremendously from his involvement with the HHT Foundation. Now, it's my turn to contribute and in the future, I expect to see our next generation stepping up as well."

From the generation of HHT members who have made a tremendous impact since the inception of the Foundation to those actively involved in the HHT community, it is your investment of time, talents and money that will create a strong HHT Foundation to be there for your children and grandchildren when they need support the most to when there is finally a Cure!

"We're paying it forward so that the future generations have more effective treatments and ultimately a cure for HHT!"

"Ways to Give Back: Personal Involvement...Financial Support...Educating Family... Advocating for HHT...Spreading HHT Awareness."