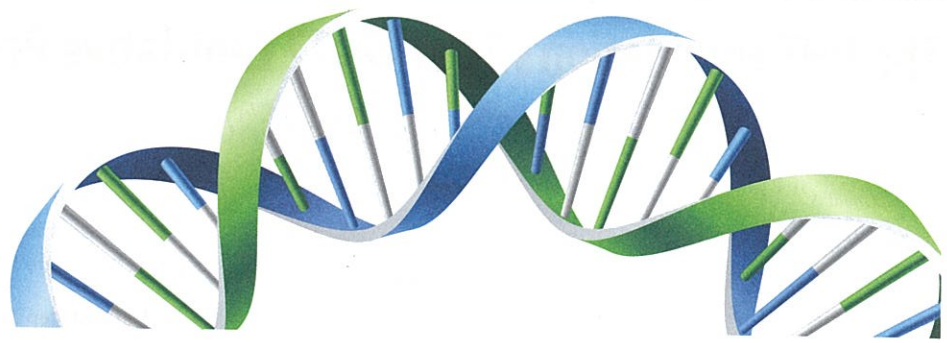


Investing in HHT

An Investment in Your Family's Future



Marianne Clancy, Executive Director of the HHT Foundation, recently sat down with an HHT donor family to update them on the progress of a research project they funded. They went on to say "Our investment in HHT has the promise of being one of the best performers in our portfolio. What makes this so interesting is, at first we thought it was charity but seeing the results of the project we realized it was really an investment in our family's future." They said their financial advisor was also in favor of them making another investment in HHT. After hearing the rest of their story, we asked if we could share it with our members. They agreed only if we could continue to maintain their anonymity. This is their story on their investment in HHT and their family.

"Unfortunately our story starts like many others with HHT. Despite numerous medical visits and tests my wife went undiagnosed for years. Our children also suffered from the effects of undiagnosed HHT. In fact, our son nearly died from lung and brain complications caused by his HHT. We were fortunate that as a result of his near-death experience we were lucky enough to find a doctor who properly diagnosed HHT in our family.

As a result of this diagnosis my wife and children were all treated at an HHT center to try and control this disease. We also became involved in the HHT Foundation and conferences and we were doing the best we could to live with HHT.

At that time, I was working for a large multi-national company. I mentioned this for two reasons, first that was back in the days of free and excellent medical insurance and second, the company policy was to give back to the community. Therefore, our state of the art medical treatment came with little out-of-pocket cost to us. Also, as part of giving back to the community, I became Allocations Chairperson for our local United Way.

I mention the United Way allocations process since it gave me a framework on how to evaluate charitable and research projects. We would use the same rigorous process years later to evaluate whether or not HHT research projects should be funded by us.

During this timeframe we looked at giving to HHT as a charity. Before I retired a few years ago, we realized that we could use professional help in managing our retirement and met with a for fee financial planner.

In setting up our financial plan, we educated the financial planner on HHT and the need to support us, our children, and grandchildren in the event there were severe complications from the disease. We also said, if possible, we would like to continue to support worthy charitable causes.

As you know, over the years, there has been unbelievable progress in the treatment of HHT and now we are talking about the possibility of a cure that would benefit our family.

That is why when we heard of possible research projects that will not go forward due to lack of money we looked to see if it was a worthy charitable cause. Examining it with the same rigorous process we used for allocation of scarce charitable funds in the past, it more than passed the test.

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The update on the research project has brought us to the realization that this is more of an investment in the health and well-being of our family than just a charitable contribution and has caused us to look at other possible HHT initiatives that are going unfunded due to lack of resources. As a result of our due diligence in this area, we have other possible investments in HHT that we have reviewed with our financial advisor. They are very supportive of this investment and have come up with a tax effective funding mechanism as part of our retirement planning.

As a side note, we are pleased with the support of our financial planner, since as I mentioned they are paid on a fee basis based upon our portfolio. So, in a way, they are also supporting this investment in our family.

We hope this new project will yield the same positive results as the last one. This is a wonderful investment in our family which can also benefit others affected by HHT. We also hope that others will be able to support the outstanding work being done by the HHT Foundation."

Money invested in the HHT Foundation is used exclusively for HHT research and education. The HHT Foundation, when possible, does not pay indirect costs to institutions and negotiates a maximum of 10% if forced to do so. The researchers agree that this is the best way to fund HHT research. The HHT Foundation International Inc. is the only organization in the world that advocates on behalf of patients to find a cure for HHT.