

March 2017

Dear Ann,

As you know, one of the responsibilities that we have taken upon ourselves is to endeavor to make certain that the supplements that are available to the FD community meet the quality control standards that are required and that there is always an ample supply of the materials. Over the years, we have expended quite some effort ensuring the ongoing availability of the tocotrienols. In 2003, we recommended a product produced by Twin Labs, but when they modified their formulation, we changed our recommendation to a product produced by Stop Aging Now. When this company informed us that they were going to stop production of the product, we sought out another quality source of the tocotrienol and had it bottled and sold by Geneva Health.

Having experienced the ongoing instability of the supply of a quality tocotrienol, about two years ago, we decided to search out an alternative product that would meet the needs of the FD community. After extensive laboratory testing of products that were being sold as tocotrienols, we settled on one product that met the standards that we had set. As this product was not derived from a rice source, we felt it necessary to evaluate the impact of these tocotrienols in those with FD. We started off by slowly transitioning a small number of individuals with FD from the Geneva product to this new product and as we found that the new product worked to ameliorate FD symptoms without any negative effects, we expanded our clinical study. As it turns out, our findings and our study could not have come along at a better time, as about six months ago, Geneva Health informed us that they were no longer going to make the tocotrienol product.

Two weeks ago, we reviewed all of the data on those in our study and we are certain that the new formulation works at least as well as the Geneva product and there has been not a single report of a negative side effect. The final step in this effort was to ensure that the product is easily accessible to the FD community and that the pricing is reasonable. With these two tasks now accomplished, we are happy to inform the FD community that the new formulation of the tocotrienols can be purchased by clicking on the following link:

<https://drrubin.ehealthpro.com/products/tocotrienol-125> . PLEASE NOTE that the new formulation, which is derived from annatto beans, is more concentrated

than the previous formulation. We are recommending that individuals with FD take two 125 mg gel caps in the AM and two in the PM. Some parents have chosen to give two 125 mg gel caps in the AM and three in the PM, which is also a suitable dose. In addition to being more concentrated, which means that those with FD have to take fewer pills, this material also has the advantage of having little or none of the standard vitamin E (tocopherols) in it. The scientific literature has suggested that the presence of tocopherols in tocotrienol preparations might somewhat mute the effects of the tocotrienols. We see the reduced level of tocopherols in the new tocotrienol formulation as an advantage.

A search on the internet will reveal that the annatto-based product is available from a variety of sources (if you want to compare them, each bottle of the product we recommend has 150 gel caps, each cap containing 125 mg of tocotrienols). You can choose to purchase this item from other vendors but please know that: 1) before using any of the annatto-derived product in individuals with FD, we performed quality control testing on the material used for the production of each lot of gel caps; and 2) we will continue to do this for each lot of material that is being sold on this site. In addition, in light of the relationship that I have developed with the company that makes the annatto-derived material, you will find that the pricing for this product is lower than the other annatto-derived tocotrienol products available from other vendors -- and the monthly cost for this new product per child will be a fraction of that of the previous product.

Finally, we should point out that the search for and evaluation of additional sources of tocotrienols for those with FD occurs because of the ongoing support provided by the FD NOW Foundation. Without the funding provided by FD NOW, this study could not have been done and the availability of the tocotrienols for those with FD would have been compromised.

If you have any questions, please address them to FD NOW and they will be forwarded to us for a response.

Best wishes,

Dr. Berish Rubin and Dr. Sylvia Anderson