



## **Harbor of Hope – Believing in Tomorrow**

Welcome to Baltimore, Maryland and the 21<sup>st</sup> National Niemann-Pick Disease Foundation (NNPDF) Family Support and Medical Conference and the 3<sup>rd</sup> Biennial Meeting of the International Niemann-Pick Disease Alliance (INPDA).

We are honored to be this year's Family Conference Hosts.

Following in the longstanding tradition of the Conference, the planned agenda provides families an opportunity to personally meet and foster connections with other families affected by the disease, as well as, an opportunity to learn about the most recent medical and research information directly from eminent researchers, doctors and scientists who work with Niemann-Pick Disease. It also provides families an opportunity for fun ~ to independently explore the vibrant and interesting City of Baltimore and its Inner Harbor, as well as, to participate in a scheduled Friday evening activities such as Dean Crawford's Notre Dame Welcome Reception & Celebration, a "Spirit of Baltimore" Harbor Dinner Cruise, a Baltimore Orioles baseball game, or the Maryland Science Center.

This year Amy Marcus and associates from The Wall Street Journal will be at the conference to gather information for an in-depth story about Niemann-Pick Disease. We are hopeful that this coverage will raise awareness. While Amy and her team will be interviewing family members, she may not be able to interview everyone. If you're interested in participating, please reach out to her.

We will also be welcoming another special guest, Dean Gregory P. Crawford, College of Science, Professor of Physics, from the University of Notre Dame. Dean Crawford has been a dedicated supporter of Niemann-Pick Disease for many years. He has spent the past four summers on cross country bike rides to raise awareness and money for Niemann-Pick Disease research. This summer he departed Los Angeles, California on June 27<sup>th</sup> for a 3,746 mile bike ride known as, "Road to Discovery", which is ending right here in Baltimore, Maryland! We are pleased to share with you all that the end of his bike ride has been scheduled to coincide with our Baltimore conference allowing us all to share in this herculean effort, welcome home and celebration!

Our hearts go out to those families who have attended previous conferences, to those who are attending for the first time, and to those who have lost a precious loved one. We are all at different stages, but we are not alone. The Niemann-Pick community is strong and has bonded together through these common soul-crushing experiences **and** connections you can only make with others in the world who can truly understand the journey we are on.

As how the Baltimorean would say....

***"Welcome to Bawl'mer (Baltimore) Hon' and enjoy the conference!"***

***Looking forward to visiting with you!***  
Mark, Darrile and Dillon (NPC) Papier