FOREWORD

Odyssey is a classic poem credited to Homer, describing Odysseus's adventures in his ten-year attempt to return home after the Trojan War. An "odyssey" by characterization is a long meandering trip or journey usually marked by many changes of luck!

In April 2014, I was invited to speak at a public hearing - the Programa Seminario Triagem Neonatal - held in Sao Paulo, Brazil on May 19-23, 2014. My assigned task was to discuss the process of how the screening test panel (Recommended Universal Screening Panel, RUSP) was originated in the US and how future disorders are added to this panel. At that time, Brazil did not have a national newborn screening program with population-based screening for an established uniform screening panel of disorders. At this meeting, I was introduced for the first time to Idario Santos (a Brazilian parent). During the coffee breaks, Idario and I spoke about his traumatic experiences with his second son who was eventually diagnosed with a metabolic disorder outside of a newborn screening program. After the meeting, he presented me with an autographed copy of his book, "*Uma Doce Odisseia.*" It was in Portuguese, and I could not even comprehend the title. Idario and I developed a friendship during our discussions. Impressed with his story, I arranged for him to present it to the US newborn screening community during the 2014 National Newborn Screening Symposium held in Anaheim, CA. His presentation was well received by the participants.

The book, "Sweet Odyssey," is a life-based, true account of a Brazilian man, Idario Santos, who finds himself for over a decade in positions comparable to those of the Biblical character, Job. Most everyone has heard of the suffering of Job in the Bible's Old Testament. Before January 2002, a couple weeks after all the excitement from the birth of his second son, Artur, Idario was extremely happy and all seemed well in his world. He was becoming well-situated financially, had a happy family and a good business in his home city of Petrolina, Brazil. Idario had no idea how his life was headed toward a dreadful existence of radical change with continuous daily trials and tribulations. Future

events and struggles were going to prove how little control that he had over life's challenges or how strong his religious faith and emotional strength were. These strengths would transform him into a man on an obsessed mission to conquer a multiplicity of barriers and challenges placed before him by odd circumstances and difficult people in places of authority.

His son began to develop medical problems a few weeks after birth and the diagnostic odyssey—the persistent search for an explanation of a health problem—was underway to first identify the cause of the problem and then to find a treatment. After a few months and numerous hospital visits, internet searching, and encounters with physicians, little Artur was diagnosed with a metabolic disorder called Maple Syrup Urine Disorder (MSUD). This began the second phase of Idario's mission to find treatment and ideally a cure while worrying about the current developing outcomes for his son during this progression. Idario had help from his families and made many new friends during his journey. The internet became his tool for seeking help and learning about the disorder that eventually lead to his chance encounter with Dr. Kevin Strauss , the world expert on MSUD. While traveling this odyssey, Idario lost all his property, wealth, job, and became deeply indebted to many people, but he never waivered from his mission or faith. His wife, first son and family stood by Idario through all the difficulties, numerous relocations and the endeavors with Drs. Holmes Morton and Kevin Strauss at the Clinic for Special Children in Lancaster, PA and with the medical staff at the transplantation center of the Pittsburgh Children's Hospital. The family unit, although stretched by the odyssey, remained intact and stronger. Idario proved that he is truly a very tenacious man who achieved his life-time desire to emulate the tenacity of his father.

The story is an adventure filled with heart-break after heart-break and occasionally joy. The described struggles and challenges were in most cases tearful and sad. The book is a first-rate read, embracing all the elements of life's experiences, including the one that frequently does not occur, a happy ending. It is amazing that the author had the

ability to retain and express all the traumas that he had faced; the intense struggles, the harsh treatments by physicians, the indifferent government officials, and the loss of all of his material possessions. I found it captivating how much a father was willing to sacrifice and the suffering he could place on his family and his first son, all for the health quest of his second son. In my career, I have heard of numerous odysseys associated with newborn screening outcomes and failures--most of which are terrible and have sad outcomes. "Sweet Odyssey" has many terrible and sad events, unbelievable challenges, but all real life happenings for someone somewhere and it ends with happiness for all. The reader learns that life's struggles require an enormous amount of faith and perseverance to perhaps achieve success -- no guarantee, but certainly one gains greater strength for future challenges. I strongly recommend this book to all parents, grandparents, newborn screeners, and healthcare professionals as a must read!!

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Short Biography

Dr. Hannon retired from the Centers for Disease Control and Prevention (CDC) with 41 years of service. He was Chief of the CDC's Newborn Screening Branch for over 25 years and retired as the Acting Branch Chief of the recently organized Newborn Screening and Molecular Biology Branch. In 1978, he created the Newborn Screening Quality Assurance Program at the CDC, which provides services to all U.S. newborn screening laboratories and to over 400 laboratories in 54 countries. He has over 250 scientific publications and has served on over 30 national and international committees for a variety of laboratory issues. Dr. Hannon co-authored standards for WHO for designing and implementing congenital hypothyroid and PKU neonatal screening in developing and developed countries. He has received many awards for his scientific contributions, including the

Robert Guthrie Award in 1999, two CDC Shepard Awards [CDC's preeminent science award] - 1992 and 2005, the 2006 Walter Dowdle Award, the 2008 Association of Public Health Laboratories (APHL)'s Lifetime Achievement Award, and the Clinical and Laboratory Standards Institute's (CLSI), Russell J. Eilers Memorial Award 2008 [the highest CLSI honor award]. APHL created the Harry Hannon Laboratory Improvement Award in Newborn Screening, which was awarded for the first time in 2008. In 2009, he received the Jeffrey Modell Foundation's "Dream Makers" Award in New York City for his contributions to early detection of primary immune deficiency disorders by newborn screening. Since retirement, Dr. Hannon has continued his work to initiate, expand and improve newborn screening worldwide.