

Freiburg or Bust

Dateline: September 19, 2014 – Freiburg, Germany

It was 60 years ago on this very same date that your intrepid reporter took his first breathe after being whacked on the behind by some hospital employee somewhere in a northern suburb of St. Paul, Minnesota. This evening, however, I find myself eating dinner at the Greiffenegg Schlössle here in Freiburg, whilst being serenaded by representatives of 26 countries with a rousing chorus of “Happy Birthday to You.” Like me, the physicians and scientists from these 26 countries were in Freiburg to attend a conference entitled, *DBA: Building Global Bridges*.

The conference was organized by Drs. Charlotte Niemeyer and Marcin Wlodarski of the University of Freiburg; Alyson MacInnes, Utrecht University, Netherlands; and Lydie Da Costa, Hôpital Robert Debré, Paris. The goal of the conference was to bring together physicians and scientists from all over the world to establish networks and facilitate the exchange of information with the goal of improving care for DBA patients on a worldwide scale. Speaking for myself, I was surprised by the scope of the conference. While I fully expected to see representatives of many European countries at the meeting, I was amazed to see representatives from the Middle East, including: Iran, Saudi Arabia, Lebanon, Israel and the Far East including, South Korea and China.

Friday the 19th was the first full day of the meeting and after introductory comments by the organizers, we began what could be described as a “Parade of Nations,” where representatives from each country gave a short talk summing up the status of DBA in their country. Each speaker used a standard template created by the conference organizers that included statistics like the number of DBA patients in their country (from as many as 720 in the North American DBA Registry to as few as 4 patients in Lithuania), treatment strategies, genetics (if known), and any challenges that might be encountered while serving DBA patients in different regions and cultures throughout the world.

In looking over the program before the conference started, I couldn’t help but wonder whether a series of talks that appeared to be largely repetitive in nature would hold my interest. I needn’t have worried; I found myself totally engrossed listening to physician after physician discussing the challenges associated with serving DBA patients in their respective countries. Some of these challenges were common to all countries whether big or small, developed or developing, but there were also problems more specific to certain countries. For example, issues relating to geography (a center in Moscow working with patients in Vladivostok 9,300 km [5,812.5 miles] away) or trying to keep track of patients in largely nomadic populations seen in certain parts of the Middle East. Societal influences can also make gathering information on things like congenital anomalies difficult, as certain cultures may be less willing to share family information. I can’t help but think that clinicians listening to colleagues from other countries received some degree of comfort in knowing that they were not alone in their challenges and that the exchange of information in a venue like this could lead to improvements in care of DBA patients throughout the world.

One of the more fascinating sessions of the day was entitled, “Challenges of the past, expectations for the future: what can we learn from the wise folks.” The wise folks here were an illustrious panel of physicians who have been working in the DBA field for many years. This panel included Jeffrey Lipton (USA), Ugo Ramenghi (Italy), Charlotte Niemeyer (Germany), and Thierry LeBlanc (France). They discussed such weighty topics as when to start steroids and what amounts to use and how they decide when to go to transplant. It should come as no surprise to readers of this

column that a topic that generated considerable discussion among members of this panel was the topic of iron overload and how this problem remains the major cause of death in the DBA patient population. It was generally agreed that there is something unique about DBA patients in how they store iron and importantly, how this leads to worse outcomes in DBA patients relative to patients with other transfusion-dependent diseases. The overwhelming consensus of all participants was that iron overload in DBA has to be a major focus going forward in both the clinical and research arenas. Many of the topics covered by these wise folks were returned to later in the day as subjects for small groups to work on in developing a new consensus document for managing DBA patients.

The day finished with short presentations from patient support groups from the different countries represented. Some of the presentations were from DBA patients, while others were from family members. These talks were very moving, and often centered on the need for patient and family resources to learn more about the disease and its various treatments. It was pointed out that many of these resources are already available on the DBA Foundation website and that a reasonable approach to disseminating these resources worldwide would be for the different family groups to work with the DBAF to translate these resources into different languages. It would also be important for these groups to work with physicians in their respective countries to determine if modifications need to be made to these documents to reflect more specialized issues relevant to some countries, but not others.

In contrast to the ICC meetings held in the United States, research took somewhat of a backseat at the Freiburg conference. This approach was certainly reasonable as the major focus of this initial meeting was to bring people together and establish networks and dialogs between physicians and scientists working on DBA on a scale hitherto not seen before.

I thank the organizers for inviting me to attend this important conference and thank all of the conference participants for their stimulating discussions and for making my 60th birthday one I will never forget.