

## Press Release

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### **Foundation Challenges African Physicians from 17 Countries to Implement Regional “Call to Action”**

New York City, New York – 25 years ago, Vicki and Fred Modell established the Jeffrey Modell Foundation (JMF) in memory of their son Jeffrey, who lost his battle with Primary Immunodeficiency (PI) at the age of 15. The Foundation is now a global organization active in 64 countries and dedicated to Research, Physician Education, Patient Support, Public Awareness, Advocacy, and Newborn Screening.

Today, the Modell’s are convening with leading physicians from 17 African Countries at the African Society for Immunodeficiencies (ASID) being held in Hammamet, Tunisia. They will be presenting a “Call to Action” with a mission of encouraging African governments to recognize and prioritize Primary Immunodeficiencies in their countries and throughout Africa. Physicians from Algeria, Benin, Burkina Faso, Cameroon, Egypt, Guinea, Mali, Mauritania, Morocco, Niger, Nigeria, Senegal, South Africa, Sudan, Togo, Tunisia and Zambia are participating in the ASID meeting.

There are more than 200 genetic defects classified under the umbrella of Primary Immunodeficiency. The U.S. National Institutes of Health estimates that 1:500 are affected and most are undiagnosed. Experts estimate that 95% of children and adults, affected by the disease in Africa, are undiagnosed and suffer with chronic, recurring and sometimes debilitating infections.

The African initiative builds upon JMF’s success in a similar “Call to Action” implemented at the European Union in 2010, and in Latin America in 2011. These programs were endorsed and signed by more than 300 signatories at the EU Parliament and more than 500 signatories in Latin America.

Vicki Modell, co-founder of the Jeffrey Modell Foundation, stated “we need to ensure that each child and adult has the best chance of being diagnosed early and effectively treated. This “Call to Action” will provide specific steps for continuous education and training for healthcare professionals in the various countries and promote equal standards of care and equal access to appropriate treatment.”

Dr. Ridha Barbouche, Chairman of the ASID local organizing committee in Tunisia, expressed his hopes. “We need to establish harmonized and comparable data sets for the region. We need common definitions and mandated criteria in order to develop comparative analysis and monitor and improve health outcomes. This “Call to Action” will contribute greatly to these goals. “

Fred Modell, co-founder of JMF added “the unnecessary suffering and subsequent burden that PI places on already over-stretched healthcare systems has already been recognized by the US Congress, CDC, NIH, the European Union Committee of Experts on Rare Diseases, and several government officials in Latin America. A dialogue between government decision-makers and the medical and patient community is urgently needed in the African region, which will drive better recognition and optimal diagnosis and treatment of these devastating diseases. Such community action will serve to address the significant disparity of care within and across African countries, will alleviate patient suffering, and free up hospital resources. This will be an historic journey.”