

The Tunisian Association for Lysosomal Disorders (ATML) had been planning to organize a round table event for parents of children with lysosomal disorders for a long time. The goal of the event was to bring parents together, creating a sense of community and support for one another as they navigate the challenges of having a child with a lysosomal disorder. One of the main challenges for these families is the lack of coverage for lysosomal disorders under national health insurance.

The SSIEM's Patient Support program made it possible for us to organize this event, despite several delays due to COVID. The event was expertly moderated by Professor Rabaa Jomli, a renowned psychiatrist. The impact of the event was significant, as parents were able to share their experiences and build connections with one another. This sense of community will be crucial as we work to advocate for the rights of our children and fight for access to the treatments and care they need.

We are grateful to the SSIEM for their support in making this event a reality and for their commitment to improving the lives of those living with lysosomal disorders.