First we want to thank the researchers for taking their precious time to participate in the 12th Annual APBDRF SAB meeting.

We know that time is of the essence. That is why it is our job to get you in the same room each year.

 This is where the magic happens, ideas are shared and developed and put into action.

There are so many people to thank.

Let me start with T and V synagogue for hosting this event. Thank you, to Rabbi Sebert, Cantor Postman and Esther our T&V executive director, who showed such flexibility in adjusting the synagogue's schedule to fit in our first **two**-day conference.

We would not be here today without our SAB leader Dr. Edwin Kolodny  who in 2005 organized  the first SAB meeting, with Gregory Weiss our founder.   Drs. DiMauro, Schiffman, Lossos, and others soon joined the effort, devoting their time and expertise. We thank you all.

We thank Gregory, too, and his family who are involved in every facet of the foundation. A special thanks to Emil and his committee for the food that we are enjoying at this conference.

There is not enough that can be said about our super empowered part-time staff, board members, and other volunteers.

Sharon our PT executive director is unparalleled in keeping the ship on course.

Harriet, a board member and secretary of the board, is inexhaustible and she is a pleasure to work with. I would say she's edited and written more than 1000 letters in the past few months.

My mentor and APBDRF consultant Jim Meier is our model of professionalism and has brought us to new levels of organizational maturity.

There are dozens of others to whom we owe a debt of gratitude including:

Members of our committees, Finance, Pharmaceutical Development, Online Presence and the newly formed Fundraising Committee.

We want to make special mention of nine families in Israel who have formed an independent sister APBD organization. They’re led by Orly Shani. They have joined the nine US families who are members of our APBDRF Board of Directors.

Together these 18 families are devoted to finding a cure for APBD.

Also, we should not forget to thank the now hundreds of donors, some of you here tonight, that have come forward in support of APBD research. You made the NYC Marathon and Penn Medical fundraisers great successes.

Finally, I wish to express our heartfelt appreciation to our scientists, physicians and orphan disease specialists. I wish I had time to name you all. Each and every one of you inspire us with your brilliance, selflessness and devotion.

I want to take a moment now to remember LD Coddon who lost his battle to APBD on Thanksgiving.

Over the last 3 decades I have gotten to know a great number APBD patients and their families. Many understandably cannot deal with more than activities of daily living and their private lives. A rare group have joined together against terrible odds to fight and give hope that we will one day end this debilitating disease.  Among those people there are a few who stand out as leaders. LD Coddon was one of them.

 LD and his wife, Susan, inspire us with their energy, wisdom and generosity.

While dealing with extreme challenges of APBD, LD Coddon facilitated six months of negotiations that led to a much-needed agreement with Columbia University. He also managed discussions leading to an agreement with Hadassah Medical Center and IP discussions with Duke University. LD developed and reviewed many other Foundation agreements and contracts and NDAs. One cannot overstate LD’s impact on how the Foundation is now viewed by the outside world. During our many discussions LD was always so humble despite his vast experience and breadth of knowledge.

I pray that these past years of working with the APBDRF gave LD hope and some small sense of satisfaction that the work we are doing will minimize the suffering of others.

To LD's family may his memory be a blessing.

To our friend and colleague.  We will miss you.

This conference is dedicated to LD’s memory.

We also deeply mourn the loss of Penny Glassman, wife of Art Glassman and sister of Sheila. Penny, Sheila and Art contributed so much to the APBDRF mission as well. You can see Sheila and Art’s videos on our website.  There they speak openly and thoughtfully about how APBD impacted their lives. Many people gravitate to the APBDRF web site to watch these videos. Those videos motivated us to continue documenting the lives affected by APBD in order to increase awareness and put a face on this debilitating disease.

With that in mind, we are honored to be able to screen the documentary "Life through a Lens" for you  today. Ronete, my daughter, and I and a talented team worked on this film for almost 2 years. Ronete is certainly the creative force behind the film. Telling the story of the irrepressible Robert Zuckerman and his journey to and past his Orphan disease diagnosis has been a labor of love.