

Experience

- Oversight of committee that created and continues to update the APBDRF website 2007-present
June 2012 – New updated website goes live
www.APBDRF.org
- Co-lead Board development committee <https://apbdrf.org/about-us/board-of-directors>
- Co-lead pharmaceutical development committee <https://apbdrf.org/research/what-were-working-on#breadth>
- Co-spearheaded committee that created Columbia University APBD Registry (CAP) 2013 <https://apbdrf.org/research/apbd-registry>
<https://apbdrf.org/wp-content/uploads/2014/05/APBDNewsletterMay2014.pdf>
- Facilitated the initiative to apply to NORD which led to the formation of the Foundation/NORD APBD (FAN) Natural History -2017
- <https://apbdrf.org/research/apbdrf-fan>
- Facilitated hiring of our first part-time executive director
- Facilitated the hiring of our part-time board, finance and compliance consultant
- Contributed to publication of periodic newsletters 2007-2018
<https://apbdrf.org/resources/newsletter-archive>
- Co-produced and co-directed the award winning APBDRF documentary “Life Through A Lens” which has appeared at over a dozen international film festivals
www.ltalthemovie.com
- Produced dozens of APBD educational and awareness videos
<https://apbdrf.org/resources/videos>
- Co-lead committee on administration of Google Adwords grant 2014-2018
- Coordinate the communication between Scientific Advisory Board and APBDRF Board
<https://apbdrf.org/about-us/scientific-advisory-board>
- Organized annual APBD NYC Marathon Fundraiser 2014-2017 raising to date over \$300K
<http://bit.ly/JojoandChloerun4APBD2017>
- Facilitated the creation of the timeline project 2017
<https://apbdrf.org/resources/timeline>
- Lead the Committee that organizes many of the Scientific Advisory Board Annual Meetings see below

- Spearheaded the initiative that lead to the inclusion of APBD in all the of NY Mount Sinai's genetic screening panels (Thanks to the works of Drs. Natowicz and Kornreich) Recently Counsyl Lab also added APBD.
- Attended and participated in the Penn Medical Million Dollar Bike Ride fundraiser
2016-2018 raising over \$270,000 to date.

Meetings

May 2018 Global Genes, RARE Patient Advocacy Symposium
Philadelphia, PA

April 2018 World Orphan Drug Congress USA 2018

January 2018 NYCEDC Intensive SBIR/STTR Proposal Prep for NIH Workshop

November 15 – 17, 2017 Rare Diseases Summit Ultragenyx, Novato, CA

November 2017 - 3 day Master Class in Orphan Drugs Terrapinn Training NYC -
New York - October 30, - November 1, 2017 Training Course

October 2017 NORD Breakthrough Summit in Washington, D. C. Panelist and
presenter at the NORD members pre-conference meeting. The program was
entitled Rare Leader Panel: Engaging Medical Professionals

September 2017 AGSD US annual meeting in Chicago

September 2017 Global Genes 6th Annual Rare Patient Advocacy Summit Hotel
Irvine, Irvine, CA

May 2017 Global Genes, RARE Patient Advocacy Symposium
Philadelphia, PA

April 2017 World Orphan Drug Congress USA

December 2016 12th Annual APBDRF Scientific Advisory Board Meeting April 15,
2015 NYC. [click here for abstracts](#)

October 2016 NORD Rare Diseases & Orphan Products Breakthrough Summit in
Arlington, VA

September 2016 AGSD US annual meeting in Toronto

May 2016 Global Genes, RARE Patient Advocacy Symposium Philadelphia, PA

April 2016 World Orphan Drug Congress USA

October 2015 Organized Israeli APBD researcher-patient meeting at Tel Aviv University <https://apbdrf.org/rabbi-levensons-reflection-on-his-recent-trip-to-israel>

October 21-22, 2015 NORD Rare Diseases & Orphan Products Breakthrough Summit in Arlington, VA.

April 2015 World Orphan Drug Congress USA Washington, D. C.

April 2015 – 11th Annual APBDRF Scientific Advisory Board Meeting April 15, 2015 NYC. [click here for abstracts](#)

October 21-22, 2014 NORD Breakthrough Summit Washington DC

December 4, 2013 – 10th APBDRF Scientific/Medical Advisory Board meeting <https://apbdrf.org/wp-content/uploads/2013/11/APBDRF-Fall-Newsletter-2013.pdf>

March 15, 2013 – 9th APBDRF Scientific/Medical Advisory Board meeting <https://apbdrf.org/wp-content/uploads/2012/09/APBDRF-Newsletter-July-2013.pdf>

June 2012 – 8th Annual APBDRF Scientific/Medical Advisory Board meeting in New York.

November 2011 – 7th Annual APBDRF Scientific/Medical Advisory Board meeting in New York.

April 2010 – 5th Annual APBDRF Scientific/Medical Advisory Board meeting in Toronto.

April 14, 2008 - 3rd Annual APBDRF Scientific/Medical Advisory Board meeting and participated in the 60th Annual Academy of Neurology (AAN) Expo in Boston

<https://apbdrf.org/wp-content/uploads/2014/04/APBDRF-Newsletter-2-2008.pdf>

March 2007 – 2nd Annual APBDRF Scientific/Medical Advisory Board meeting and participated in the 59th Annual Academy of Neurology (AAN) Expo in Boston.

August 1, 2006 – Attended the APBDRF sponsored first international conference at NYUMC of recognized medical professionals to discuss the state of research on APBD. The conference laid the groundwork for the coordination of future research on APBD. <https://apbdrf.org/wp-content/uploads/2014/04/APBDRF-Newletter-1-March-2007.pdf>