

A Message from President Adam Gumson Special Edition: AICARDI AWARENESS DAY



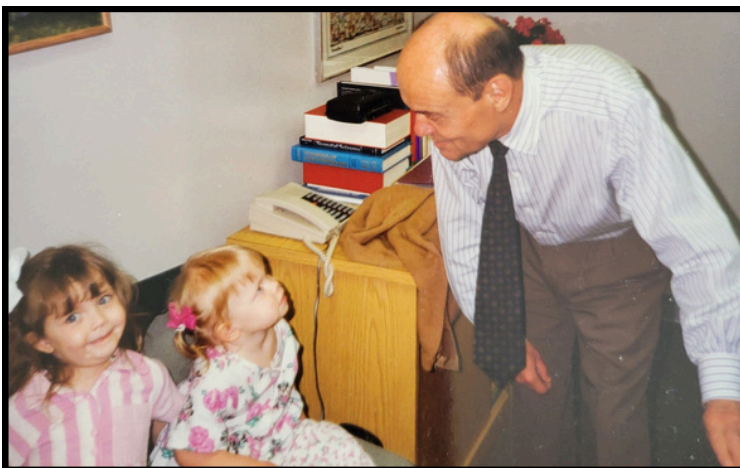
Happy November to all of you!

Aside from kicking off the next 2 months of holiday chaos, November is also the birth month of Dr. Jean Aicardi, the distinguished French pediatric neurologist and epileptologist who first identified the disorder that bears his name: Aicardi Syndrome. He was born on November 8, 1926 (and died on August 3, 2015) and Saturday, November 8, 2025 would have been his 99TH birthday.

In addition to his discovery of the disorder that binds all of us together, he also taught legions of doctors, nurses and students at various children's hospitals, including Miami Children's Hospital. My wife and I and our daughter Ava met him in 2006 there. November 8TH is celebrated worldwide as Aicardi Awareness Day in his honor – so be sure and wear your purple Aicardi shirts and proudly wave your Aicardi Syndrome Awareness flags on November 8TH!

P.S. On October 3, 2025, NBC ran a national story about our very own Patrick & Carrie Lazo and their daughter Emmalyn "Emmy". They have been battling insurance companies regularly denying them basic medicines and medical devices, that their doctors prescribed for Emmalyn. It is a battle we have all waged and unfortunately, continue to wage. Kudos to the Lazoens for sharing Emmy's battle and shedding light on this travesty of justice. The link to the NBC segment is posted in the "News" section on our website. Here is the link: www.aicardisyndrome.org/news/

P.S.S. Stay tuned for our Aicardi Syndrome Foundation Winter Newsletter in early December, when I'll update you on a host of latest Aicardi-related news since our July Family Conference. This update will include a number of successful fundraisers and active committees being formed to facilitate the Aicardi Syndrome Foundation's growth and outreach goals.



Dr. Aicardi with Caitlin Hoel & her sister Megan



Dr. Aicardi with Anne-Lorène (Lolo) Perroux, Olivia Klopfenstein, Ellie Ringer & their mothers.