

Cindy Parseghian

Ara Parseghian Medical Research Foundation



Title President of APMRF

Biography

Cindy Parseghian has dedicated her life to founding and directing the Ara Parseghian Medical Research Foundation in hopes of saving the lives of her children, and hundreds of other children and young adults around the world afflicted by Niemann-Pick Type C (NP-C) disease.

Niemann Pick Type C disease took the life of Cindy and Mike Parseghian's second oldest child, Michael, in 1997. Christa passed away at age ten in October 2001, and Marcia in August 2005 at age 16.

In 1994, just months after learning that three of their four children had NP-C disease, Cindy founded the Ara Parseghian Medical Research Foundation with help from her father-in-law, Ara Parseghian, the legendary Notre Dame football coach.

The Foundation's purpose is to fund research and promote worldwide interaction amongst scientists, research institutes, universities and pharmaceutical companies working on NP-C and related diseases in hopes of finding a treatment and cure. The number of labs working on NP-C has increased from less than 5 to more than 60 worldwide since the inception of the Foundation.

Cindy is responsible for long-range planning and administration, and has overseen more than 150 medical research projects funded by the Parseghian Foundation across the US, Canada and Europe.

The Parseghian Foundation has sponsored an annual Scientific Conference on NP-C disease each year since 1995. This conference attended by researchers and NP-C families, is critical for the discussion, collaboration, latest developments and deciding the future direction in NP-C research. Through an endowment made to the University of Notre Dame, College of Science, this conference continues annually at the University of Notre Dame.

Of the more than 400 rare disease organizations in America, the Parseghian Foundation is a leader in raising funds and awareness. In nineteen years over \$40 million have been raised.

Administrative costs are held to a bare minimum due to the dedicated support of Tucson volunteers, where the Foundation is based, volunteers across the country including many Notre Dame alumni, as well as other NP-C families. Over 85% of all funds raised go toward research.

Although her heart is broken having lost Michael, Marcia and Christa, her passion and commitment are stronger than ever to raise the funds necessary to find a treatment and cure for all children living with NPC. Hopefully other families will not have to experience what she and her family have gone through.