

November 2016

Dear Alstrom Family and Friends,

As most of you receiving this appeal are aware, Jan Marshall, my wife, partner, and best friend for the better part of 50 years, died of a pulmonary embolism in early September, an almost incomprehensible loss to not only her immediate family but to all those who knew her, especially those who inhabit Alstrom Land. A dear colleague of Jan's said it well: "It is so rare that the spirit of scientific rigor and enquiry is matched and exceeded by the capacity and drive not just to touch people's lives but truly transform them. A smile, a big hug and so much compassion, soaking up the sorrows and anger and anxiety, listening and understanding, then doing something to help."

Another unknown admirer offered solace to an Alstrom Mom by quoting an African proverb that states, "When a knowledgeable person dies, a whole library disappears." And then, importantly, she added, "but Jan will have left seeds and sprouts behind." To a certainty I can reassure you that those seeds have been sprouting and growing for several decades. Many are already sturdy saplings; many are mature trees; a few are already towering oaks and doing their own part to propagate and guarantee the future of Alstrom Syndrome International and its affiliates throughout the world! Jan is still working in that her death has engendered a renewed commitment within ASI's scientific community to the central mission of treating and ultimately curing Alstrom Syndrome.

ASI has had a remarkable year! With your help, our core programs (Research, Education, and Family Support) have never been stronger! We also secured the largest award in our history to support the 8th International Family Meeting and Science Symposium which focused on fully engaging all stakeholders, whether in physical attendance or not, in the process of identifying and pursuing research priorities. Thirty-eight globally recognized professionals attended along with 233 children and families of whom 127 traveled from around the world. With your help, we funded an additional Alstrom-specific multidisciplinary clinic at Greater Baltimore Medical Center, an effort on the road to establishing an Alstrom Syndrome Center of Excellence! With your aid we sponsored an A-Team Retreat, a four-day leadership event attended by thirteen of our adult patients that was an unqualified success! With your contributions and with support from Alstrom Syndrome Canada and Alstrom Angels, ASI facilitated the molecular diagnoses of an additional 30 patients! With your support, we continued to work productively with Genetic Alliance and the CENA (Community Engaged Network for ALL) project to establish ARC (Alstrom Research Connect and Family Exchange), an online patient registry intended, in part, to foster scientific research.

Though each and every one of these initiatives was part of Jan's extraordinary vision and tireless efforts, she was certainly not alone in planning and executing any of them! Though it may take all of us to equal what Jan did singlehandedly all these many years, we assuredly can and will finish the only job she ever wanted for herself – treating and curing Alstrom Syndrome! I give you my pledge that the Governing Board, the Scientific Advisory Board, and our fantastic cadre of volunteers will keep the torch burning bright!

Please honor Jan with your contribution and help lift the torch even higher and burning even more brightly

Thank you and best wishes,

Robin

Please be advised that Jan D. Marshall passed away in early September. Her work and that of Alstrom Syndrome International WILL continue. If you have questions, please feel free to contact Robin Marhsall, Jan's husband and a co-founder of the charity. Robert (Robin) P. Marshall, Executive Director, Alstrom Syndrome International, 14 Whitney Farm Road, Mount Desert, ME 04660 USA. Ph: (207) 244 7043; Fax: (207) 244 7678; robin.marshall@alstrom.org; www.alstrom.org.

SOMESVILLE, MAINE

Jan Davis Marshall of Somesville died unexpectedly on September 6, 2016, leaving her wide network of family, friends and the genetics research community at Jackson Laboratory stunned by her passing.

Her dynamic life began in western New York on February 17, 1948 and remained full of extraordinary energy and accomplishments throughout. She was the daughter of the late Thomas J. and Betty (Walker) Davis of Williamsville, New York and Somesville.

She is survived by her husband and soul-mate Robert (Robin) P. Marshall, beloved daughter Erin (Richard) Cyr, her grand-daughters Madison and Lily of Carver, MA., and sister Susan (Paul) Belanger of Madison OH. Many others, including a legion of Deck House Players considered her to be friend, sister, or mother. All will remember her passion for life, her love of great food and wine, and the joy she found in sailing the waters of Mt. Desert Island with her precious grandchildren.

Jan graduated from Williamsville High School and from Hartwick College in Oneonta, New York before moving to Mt. Desert Island with Robin in 1970 to start her career as a Research Assistant at the Jackson Laboratory where she was a Senior Professional Assistant and Genetics Coordinator for Alström Syndrome Studies at the time of her death.

During her 46-year career at Jackson Laboratory she contributed to many genetics research projects as a valued team member. However, it was her research on Alström Syndrome, a rare and very serious inherited disease, that captured her passion and became her most important legacy, making a huge difference in the lives of Alström patients and families in 58 countries.



Jan located and worked with these families and children to develop and maintain ongoing research that facilitated the discovery of the gene, ALMS1, in 2002. She also developed a very deep and very personal commitment to helping the Alstrom Family – anyone affected as well as all other stakeholders. In 1998, she and Robin founded Alström Syndrome International (ASI), a charitable organization dedicated to treating and curing the disease. She authored or co-authored over 75 scientific articles and The Alström Syndrome Handbook, all of which have greatly increased the worldwide understanding of the syndrome. A colleague said it well: “It is so rare that the spirit of scientific rigor and enquiry is matched and exceeded by the capacity and drive not just to touch people’s lives but truly transform them. A smile, a big hug and so much compassion, soaking up the sorrows and anger and anxiety, listening and understanding, then doing something to help.”

Her legacy survives in the hundreds of families around the globe that now have been helped by ASI and the continuing research on the disease. She has touched many lives and remains an inspiration to all who knew her. Her lifetime awards include the Galileo Galilei Surgical Theater Medal for Scientific Achievement from the University of Padua, Italy (2003) and the Williamsville Education Foundation Wall of Fame Award for Distinguished Service to Science (2008).

Tax deductible (USA only) memorial contributions in Jan's honor may be sent to Alström Syndrome International, 14 Whitney Farm Road, Mt. Desert ME 04660 in support of the programs (Research, Education, Family Support) maintained by Alstrom Syndrome International.