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November 2022

Dear Alström Family and Friends,

While contemplating writing this letter, I thought about what you need to know to make an informed decision before apportioning your charitable giving. So, if you are unfamiliar with Alström Syndrome, or even if it is well-known to you, please take the time to access the following testimonials presented by several extraordinary Alström mothers this past September as part of the FDA's Externally-Led Patient Focused Drug Development initiative. <https://videos.ziamedigroup.com/67t6mneo> ; [AS Global Conference The three amigos! - YouTube](#). These children, their families, and their doctors truly are warriors locked in battle!

Although great variability exists, Alström Syndrome remains a particularly vicious genetic disorder affecting children of all ethnicities. All will go blind and partially deaf. Most will battle diabetes. Most will struggle against congestive heart failure, liver and kidney disease, respiratory, and urological problems. At present, most will prematurely succumb. We all carry this gene that "malfunctions" in our Alström children but solving the riddle of Alström Syndrome could well help those in the "normal" population who suffer from many of these very same health issues!

The mission of ASI is: *To provide support, information, and coordination world-wide to families and professionals to treat and cure Alström Syndrome.* To that end, we maintain three very proactive programs: Research, Education, and Family Support. Not a *single* day passes without attention being paid to these programs and to the projects under development within them. A visit to our web site at [www.alstrom.org](http://www.alstrom.org) will reassure you that we are clearly focused on the mission and that your contribution will be used *exclusively* to further these dynamic, productive, and essential efforts. If you have given in previous years, you can readily see the difference that *you* have already made in confronting what one mother characterized as "this monster that lives within my child."

Our greatest concern at present, in addition to sustaining our extant programs and initiatives, is securing support for the 9<sup>th</sup> International Family Conference, Medical Clinic, and Scientific Symposium that ASI will host in October of 2023, now less than a year away. With your financial help, and the participation of the hundreds of people expected to attend, the conference will address several central issues. Importantly, the many families denied medical care, and families who have never met another child with Alstrom, will receive a comprehensive understanding of the health, educational, and social issues that confront them. In addition, physicians and researchers will share, learn, consult, and network. These are the goals that will be attained at this global gathering with *your* support!

My personal passion and that of the hundreds of wonderful people with whom I work is to help these fantastic kids and to ultimately rid the world of this devastating disorder. While accepting the importance of other causes, few, for me, can truly compete with the immediacy and the urgency of a hug from an Alström child or the plea in a parent's eyes. For ease of donation, please go to [Donate to ASI – Alström Syndrome International \(alstrom.org\)](#). On behalf of the children and families we represent: Thank you for caring! Thank you for making a difference! Thank you for your generosity!

Sincerely,

*Robert P. Marshall*

Robert P. Marshall  
Executive Director

*Drop by Drop we form a lake!*