

Becoming President of the Board of Directors in 2010 of the American Syringomyelia & Chiari Alliance Project.

ASAP wrote then, and I wrote then. Me first:

A Word from Our President

"As I begin my term as President of this passionate organization, it seems fitting to dedicate the year 2011 to the memory of Barbara and Don White, our founders, and to rededicate the organization to the goals that they so effectively championed for over twenty years.

When my daughter was first diagnosed with Chiari/SM in the mid 1980's the Internet was something most of us knew nothing about and the MRI at Children's Hospital of Philadelphia was just being installed. There was no place to find support and information about the condition. The White's were the first to begin remedying that with the founding of ASAP. Their goal of providing support and information has made the lives of hundreds of thousands a little bit less stressful as they chart a course of treatment for these conditions. Our website, www.ASAP.org, remains the most visited site related to Chiari/SM in the world.

But as sophisticated technology has shown a dramatic increase in Chiari/SM diagnosis, we have also seen an increase in the number of organizations trying to help. The National Organization of Rare Diseases now shows over fifteen such groups worldwide. Working together we can move more quickly to finding a cure. As the leader in this effort ASAP must continue to fund patient information and support and the vital research which the esteemed members of our Medical Advisory Board pursue every day.

So, as I begin my term, I ask all of you who read this to think of some way to be involved. Whether through contributions of ideas, time or money, we need you to be part of the ASAP family as we continue to stand beside all those battling these debilitating conditions.

Very truly yours,

Don Williams"

ASAP:

"After graduating from Yale College and Law School he practiced law and was involved in various business ventures, including founding Carnegie Bank in Princeton, NJ. At his retirement he was a principal in the Breen Capital Group, a financial investment firm.

His oldest daughter was initially diagnosed with scoliosis in 1978 and some years later, with the introduction of the MRI, with Chiari* and syringomyelia**. She has endured over a dozen surgeries, the most recent at Johns Hopkins in 2010. She is a psychotherapist in private practice in Washington, D.C. where she lives with her husband.

His younger daughter began her career in banking and now is the mother to Don's two grandchildren. The family lives in Manhattan. His step-daughter, also a psychotherapist, recently moved back to Philadelphia after three years in Chicago.

Don has lived for the past ten years in New Hope, PA. He and his wife, Diana, live in a tenant cottage built in 1731, the upkeep of which takes virtually all of their spare time. Whatever time is left, after the grandchildren, is spent sailing on the Chesapeake or making offshore trips to the Caribbean."

* "the most common cause of syringomyelia, where the anatomic abnormality, which may be due to a small posterior fossa, causes the lower part of the cerebellum to protrude from its normal location in the back of the head into the cervical or neck portion of the spinal canal. A syrinx may then develop in the cervical region of the spinal cord."

** "a generic term referring to a disorder in which a cyst or cavity forms within the spinal cord"