

## *Importance of Research in the African American Community*

**Hope DeVougas, Milwaukee, WI**

### **One Family's Journey**

Hope is the primary caregiver for her 86-year old mother, who is living with Alzheimer's disease. Her father, who passed away in 2013, also had Alzheimer's disease. "My father developed Alzheimer's the last year of his life," says Hope. "At the time, we didn't see the signs or recognize it. However, now there is so much more awareness of the disease and we saw the signs earlier when my mom started to show symptoms." In Wisconsin alone, there are over 195,000 caregivers, many like Hope, who balance family and work demands.



Hope (second from right in front row) with her 5 siblings surround their mother.

### **Research Study**

In 2020 Hope began participating in a lifestyle intervention study through the Wisconsin Alzheimer's Institute at University of Wisconsin-Madison. This study is focused on African Americans whom one or both parents have/had Alzheimer's disease. Hope underwent testing to benchmark her health – memory tests, as well as medical tests (diabetes, heart, etc.). In addition, the study also looks at environmental factors – how she was brought up, stress factors and things she was exposed to (e.g. racism). The study looks at all these factors and if they have an effect of escalation of Alzheimer's disease. She will check in every 2 years to benchmark changes in her health. "We can learn so much about the disease through research," says Hope. "Some things are genetic and the more we can prepare ourselves, the better it will be."

### **Overcoming Fears**

"Many African American folks get skittish when it comes to research studies," says Hope. "Even my siblings did not want to participate in the study because it's often scary to think about. To know that you are going to depend on someone to care for you is overwhelming. But research is so critical and needed to help slow the progression of this terrible disease."

Hope acknowledges her family didn't understand the impact of Alzheimer's until it affected their family. Since the time of her parent's diagnosis, Hope's entire family has become more involved in the Alzheimer's community and participate in the Walk to End Alzheimer's.

### **Creating Awareness**

"Organizations like the Alzheimer's Association are doing a great job for creating awareness and sharing resources," says Hope. "When I was younger, you never heard about dementia or Alzheimer's, but rather people were just "getting older," says Hope. "It's important that people are aware and know the risk factors. I want to prepare my children for what could impact them."



In addition to her caregiving duties, Hope works for Congresswoman Gwen Moore coordinating Constituent Services. She is surrounded by advocates for Alzheimer's disease as Congresswoman Moore supported a \$350 million increase in funding for Alzheimer's research in fiscal year 2020. The Alzheimer's Association is advocating for an additional \$354 in research funding in FY21.