# CARE & FEEDING OF RESEARCH ADVOCATES

SANDI SPIVEY

**RESEARCH ADVOCATE** 

HRA WEBINAR 3-31-2020

## A FABLE

















## ADVOCATES PARTNERING WITH RESEARCHERS

- Effective
- Essential



#### PLANNING A RESEARCH ADVOCATE PROGRAM



**Support from the top** 



Roles & responsibilities Design intentional and meaningful interactions.



Include a training plan:
Researchers & Advocates



No financial burden on advocates.

#### SELECTING ADVOCATES

PHD – Personal History of Disease - as a patient or caregiver

Connected to and represent their communities.

Advocates should not be researchers

#### CONDUCTING THE ADVOCATE PROGRAM



Include advocates from the start



Acknowledge Advocate's work. Include them in presentations



Develop a mentorship program

FOLLOW UP & REVISE

Listen Listen. Maintain program flexibility Observe Observe the process Don't Don't trash the program trash

GREAT ACTS ARE MADE UP OF SMALL DEEDS – LAO TZU

## BE PATIENT



### THANK YOU

#### Advocates:

- Cheryl Jernigan
- Christine Hodgdon
- Julia Maues

