

# **PATIENT ENGAGEMENT AND THE GREATER PLAINS COLLABORATIVE**

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**WHO & WHAT ARE  
*PATIENT RESEARCH  
ADVOCATES?***



# PATIENT RESEARCH ADVOCACY...

*“I don’t know how to study pain...but I am an expert in living with it.”*

*~Jeff Ordway*



# WHO ARE *PATIENT RESEARCH ADVOCATES*?

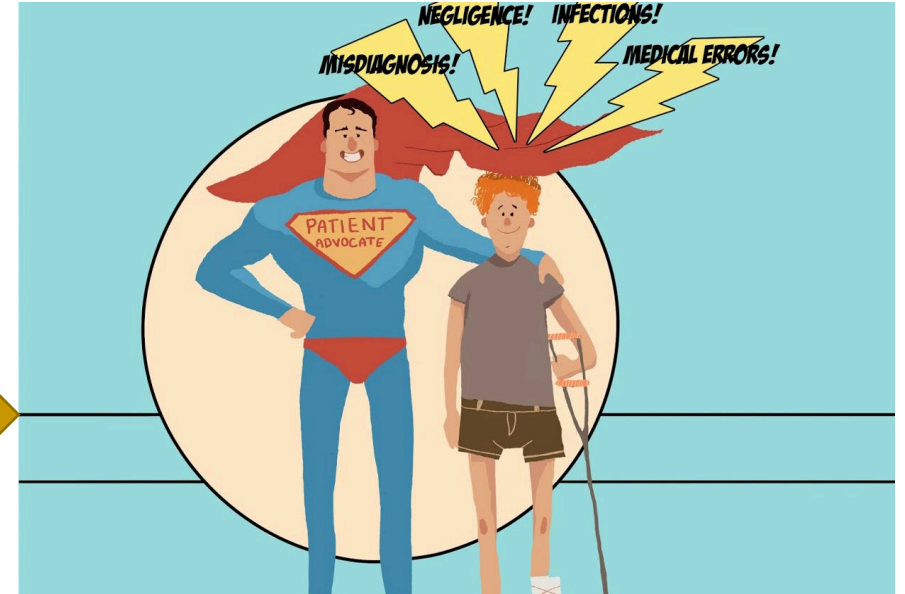
- Preivors, survivors, co-survivors, caregivers, patients, family members
- Interested in medical research
- Committed to self-development & education about biomedical science
- Ideally, tied to a broader community so that they can share a *collective* patient point of view & insights



# DIFFERENCES

## Patient advocates

People who advocate for and on behalf of a patient



## Patient RESEARCH advocates

People who advocate for science and research that drive better patient care and outcomes



# **WHAT DOES A *PATIENT RESEARCH* *ADVOCATE OFFER?***

We add:

- A non-scientific viewpoint
- Lived experience & expertise
- A collective patient perspective
- An urgent focus on what matters most to patients



# **WHAT DOES IT TAKE TO “SPEAK RESEARCH”?**

**Jeff Ordway**



# SPEAKING WHALE

We use the next slide or, we play the whale video from Finding Nemo

[https://video.search.yahoo.com/yhs/search;\\_ylt=AwrC3CKVH99gsHAAWwUPxQt.;\\_ylu=Y29sbwNiZjEEcG9zAzEEdnRpZAMEc2VjA3BpdnM-?p=finding+nemo+speaking+whale&vm=r&type=dkff\\_8679\\_FFW\\_ZZ&hsimp=yhs-3&hspart=iba&grd=1&ei=UTF-8&fr=yhs-iba-3#id=1&vid=c672e67186ba5f380a65a726d0048eb0&action=view](https://video.search.yahoo.com/yhs/search;_ylt=AwrC3CKVH99gsHAAWwUPxQt.;_ylu=Y29sbwNiZjEEcG9zAzEEdnRpZAMEc2VjA3BpdnM-?p=finding+nemo+speaking+whale&vm=r&type=dkff_8679_FFW_ZZ&hsimp=yhs-3&hspart=iba&grd=1&ei=UTF-8&fr=yhs-iba-3#id=1&vid=c672e67186ba5f380a65a726d0048eb0&action=view)







Before I heard your lecture, I was confused.  
I am still confused, but on a much higher level.

Enrico Fermi to J. Robert Oppenheimer



# PATIENT RESEARCH ADVOCATE GUIDANCE

- Researchers spend years learning how to speak “whale”/research. They are rewarded for it.
- Researchers rarely engage with patients, families & caregivers. You are a new experience for them!
- Be patient & persistent. If you have a question, chances are pretty good someone else does, too.
- Synthesize what you hear, ask questions to understand the point of the study – that’s where to start



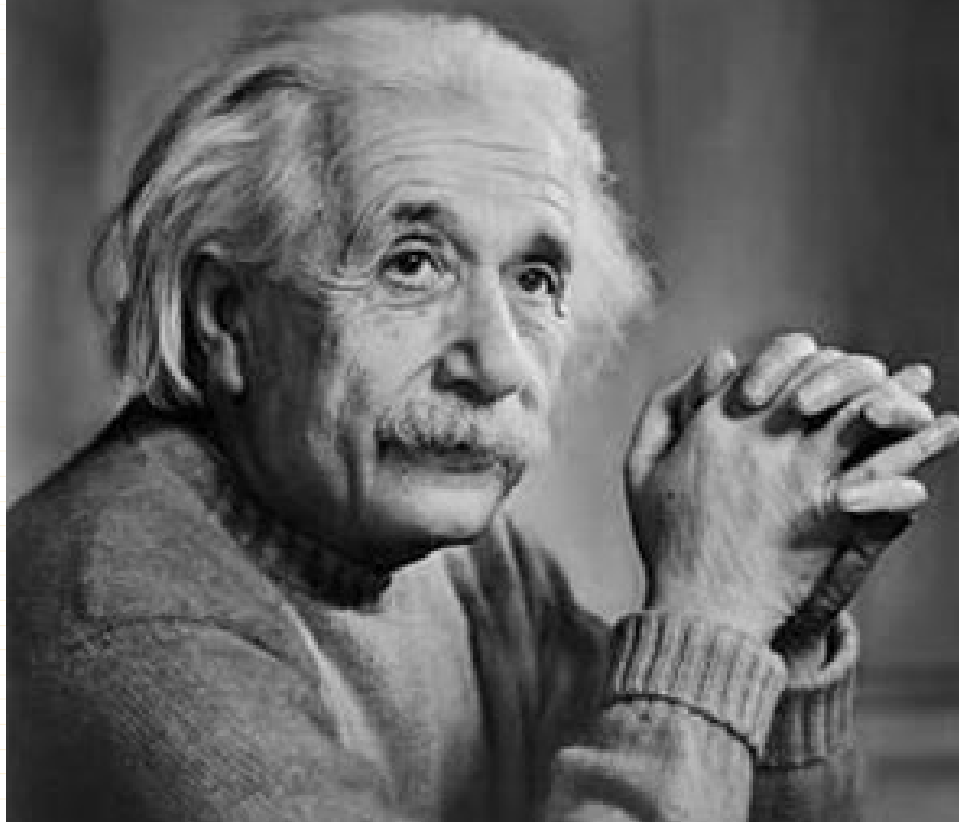
# **WHAT DOES IT TAKE TO “SPEAK PATIENT”?**

**Kim Kimminau**



If you can't explain it **simply**, you  
don't understand it well enough.

– Albert Einstein



# RESEARCHER GUIDANCE

## 1. Impart the impact

- How is your research going to affect people?

## 2. Tell a story

- Anecdotes, not data, are what tend to leave a lasting impression

## 3. Use “plain speak” or what is called “**living room language**”

While you may not think that there’s anything a patient could possibly add to your science, think again



# EXAMPLES OF PATIENT PARTNER INSIGHTS THAT TRANSFORMED RESEARCH

1. Barohn: CSPN patient outcomes
2. Mustafa: PKD priorities
3. PIVOT lab science+patient dyads



**THANK YOU AND QUESTIONS?**

