

**TOGETHER, PATIENTS AND CANCER RESEARCHERS
CAN ADVANCE MORE BREAKTHROUGHS.**

NAS Workshop on Innovative Person-Centered Clinical Cancer Research

**Julia Maués
Co-Founder**



**GUIDING RESEARCHERS & ADVOCATES
TO SCIENTIFIC PARTNERSHIPS**

About Me



When I was 29 years old and 25 weeks pregnant



Diagnosed with breast cancer



Treatment during pregnancy: CHEMOTHERAPY



At 37 weeks, I gave birth to a healthy baby boy, full of hair (while I was completely bald)



Post-delivery scans showed the cancer left the breast and spread to brain, liver and bones

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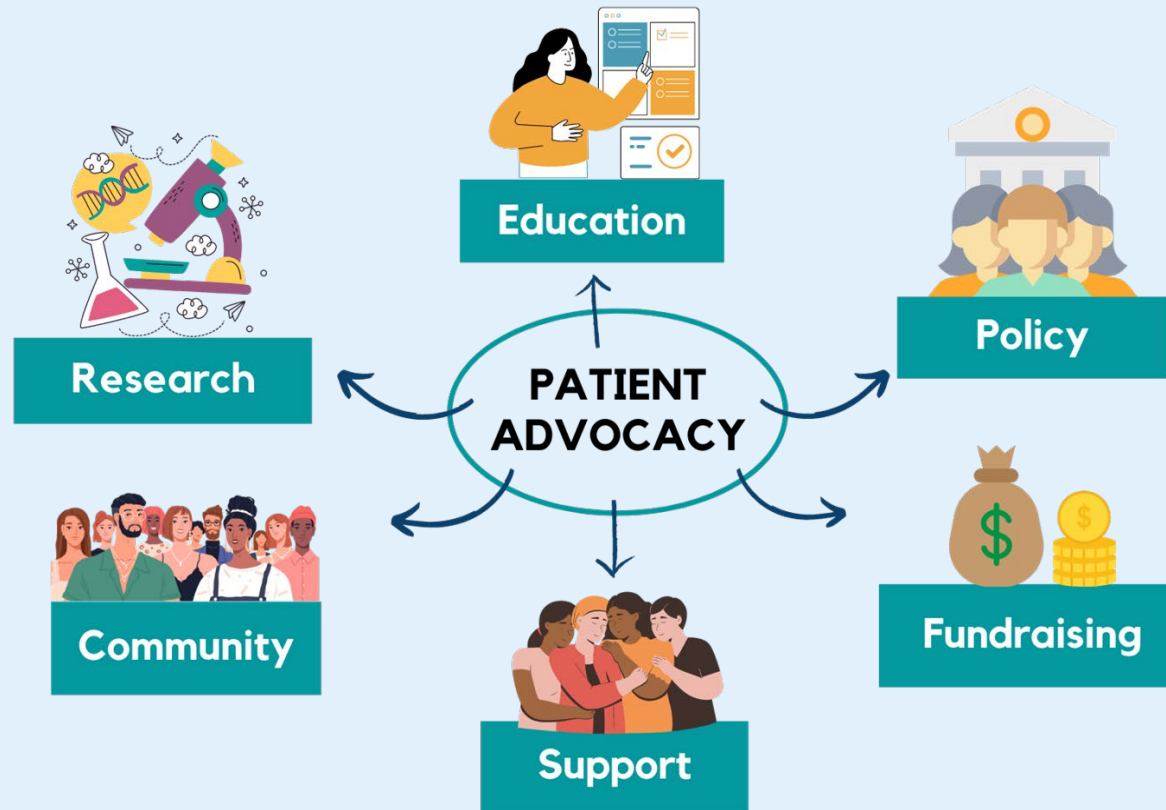


**SPOILER
ALERT!**

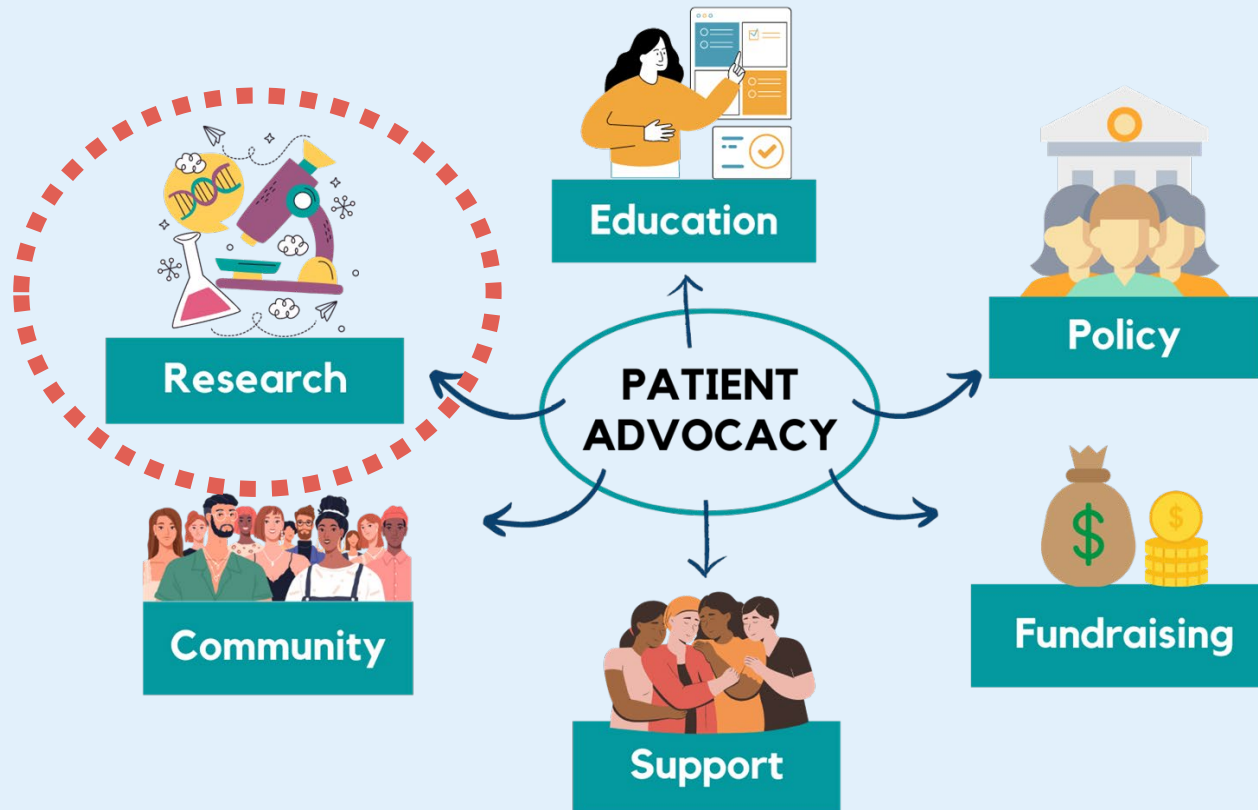
That baby
is now 12
years old!



Patient advocacy has many paths



Patient advocacy has many paths



Advocacy in Research: Why It Matters

Researchers



- Brings meaning and urgency
- Expands public understanding of science
- Reduces burnout, inspires new talent
- Improves real—world impact

Patients



- Hope for longer, better lives
- Knowledge about their disease
- A voice in shaping the studies
- Trials that are practical and patient-friendly
- Shines light on treatment challenges that are often ignored



Why Person-Centeredness?

Doctors



Patients



“Oncologists most valued gains in survival, whereas patients valued treatments that enhanced quality of life.” (Dilla 2016)



Barriers to Patient-Researcher Interactions

Researchers



- Where do I find patient advocates?
- I don't have cancer, how do I talk to patient advocates?
- How do I compensate advocates for their time?

Patients



- Where do I find researchers interested in working with patient advocates?
- I don't have a science background, how do I talk to researchers?
- How am I valued for my expertise?

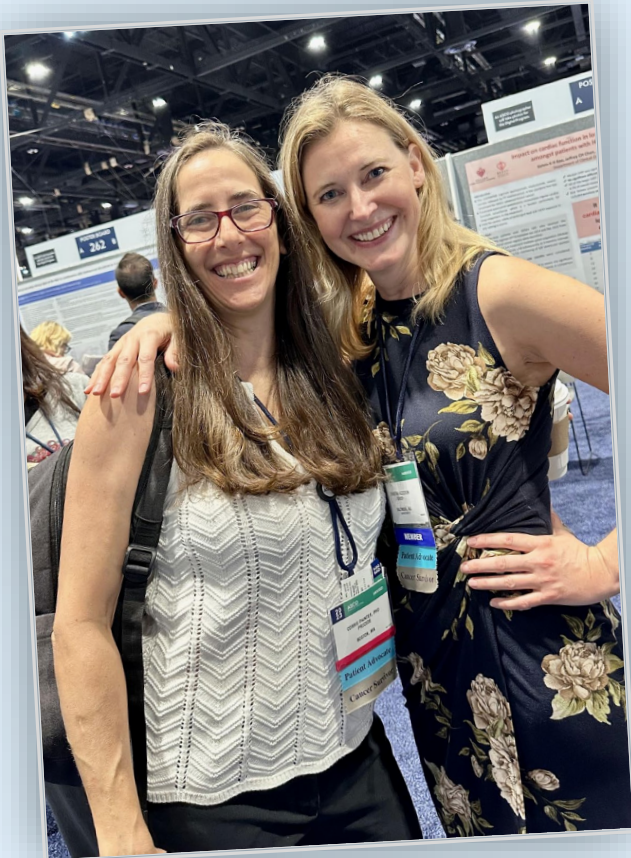


**But how do patients and
researchers find each other?**



How GRASP began...

...Opportunities for researchers, clinicians, & patient advocates to collaborate are limited



GRASP Philosophy



- Bring scientists & patients together as **equal partners**
- Create **bidirectional** learning opportunities
- Add **value** to cancer research
- Hone communication skills
- Bring patients **HOPE** through research



Connections and Bidirectional Learning



GRASP



Who We Serve



Cancer scientists:
Including clinicians &
researchers



Advocates: Including
patients
& caregivers





VIRTUAL LINKUPS

LOG ON & LEARN



Poster Walkthroughs – Virtual post-conference discussions about cancer research



Huddles – Freestanding interactive cancer research discussions



Network – Connections to our network of advocates & researchers

Virtual Program Offerings



In-Person Program Offerings



IN-PERSON MEETUPS

EMPOWERING THROUGH EXCHANGE



Poster Meetups – In-person discussions about research at cancer conferences



coming soon

Lab Meetups – Patient advocate visits to cancer research labs



Receptions – Social gatherings between advocates & researchers



“These interactions **critically enhance** the translational aspect of my research. GRASP also helped me network with patients and researchers associated with rare forms of cancers like male breast cancer.”

Meenakshi Anurag, PhD

Baylor



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Thank you!

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