

# Shared Decision Making Learning Community Meeting #2 Patient Experience and Shared Decision Making

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May 5, 2025  
9:00 a.m. – 10:00 a.m.

Washington State  
Health Care Authority

# Meeting Agenda

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- ▶ Welcome/Introductions
- ▶ Identifying ICU Gap – Angelo Volandes, MD, MPH & Aretha Delight-Davis, MD, JD
- ▶ Patient Experience - Baby J's Story – Mandy Lee, MSN, RN, CCM
- ▶ NICU Patient Aid Demo - Angelo Volandes, MD, MPH & Aretha Delight-Davis, MD, JD
- ▶ Wrap Up

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- ▶ Wrap Up

# Welcome and introductions

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Please briefly share in the chat:

- ▶ Name
- ▶ Organization
- ▶ Interest in learning community
  - ▶ Newbie
  - ▶ Some experience
  - ▶ Expert

# Identifying ICU Gap

Angelo Volandes, MD, MPH & Aretha Delight-Davis, MD, JD,  
ACP Decisions



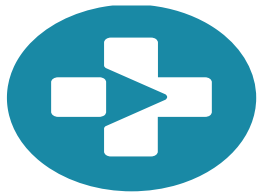
# Video Library

|                                                                                                             |                                                                                                                   |                                                                                                             |                                                                                                               |                                                                                                                       |                                                                                                               |                                                                                                        |                                                                                                          |
|-------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| <br>Hospice                | <br>CPR                          | <br>Goals of Care          | <br>Advance Directives     | <br>Caregivers                     | <br>Home Health Care       | <br>Assisted Living | <br>Pediatrics        |
| <br>COVID-19               | <br>Advanced Cancer              | <br>Advanced Heart Failure | <br>Advanced Dementia      | <br>Advanced Disease               | <br>Bone Marrow Transplant | <br>CHG Treatment   | <br>Intubation        |
| <br>Advanced Renal Disease | <br>Advanced Lung Disease        | <br>Advanced Liver Disease | <br>Advanced Heart Disease | <br>Advanced Dementia (Caregivers) | <br>Cancer Screenings      | <br>Healthy Adults  | <br>Understanding ACP |
| <br>ICU                  | <br>Skilled Nursing Facilities | <br>Palliative Care      | <br>NICU                 | <br>Surgery                      | <br>Immunotherapy        | <br>Immunizations |                                                                                                          |



# Video Languages





# Video Languages

- American Sign Language
- Arabic
- Cantonese
- English
- English (Pascua Yaqui)
- German
- Greek
- Haitian Creole
- Hindi
- Ilocano
- Italian
- Japanese
- Korean
- Mandarin
- Marshallese
- Navajo
- Nepali
- Persian
- Portuguese (Brazilian)
- Russian
- Samoan
- Somali
- Spanish
- Tagalog
- Urdu
- Vietnamese

# Baby J's Story

Mandy Lee, MSN, RN, CCM



# Baby J's Story





# The future I dreamed

- ✓ MARRY SOMEONE WONDERFUL
- ✓ HAVE TWO BABY GIRLS 15 MONTHS APART
- ✓ LOVE THEM, RESPECT THEIR PERSONHOODS, RAISE THEM TO BE LOVING HUMANS
- ✓ LIVE HAPPILY EVER AFTER

# Jordan

Wise spirit

Old soul

Badass baby



Epidermolysis Bullosa –  
Rare genetic skin condition  
that causes blistering



A close-up photograph of a young child with light brown hair and a purple hair tie. The child's face and chest are covered in blood, with a visible wound on the forehead and a bloody mark on the chest. The child has a distressed expression, with wide eyes and an open mouth. In the background, the lower part of another person's face and a white shirt are visible, though out of focus.

I know Mom doesn't want to hurt me.

<https://youtu.be/X3PluWEEnEF4>

# Informal Shared Decision-Making

Our providers never told us what to do. They **asked us what we wanted for our baby.**

We were encouraged to ask questions.

They took the time to help me understand the details and potential outcomes of interventions.

Our pediatrician and dermatologist worked together behind the scenes to present education and options in one space instead of hearing from multiple specialists in multiple places.

We felt empowered to protect our daughter ourselves. We were allowed to be her parents. Providers were there to support us in parenting, not to make decisions for our family.

Thank you to Dr. Noreen Womack, Dr. Steven Mings, Rae Bauman RN, Connie Hutchison RN, and the Boise Fire Department for the loving care you offered our family!



# SDM's gifts to our story

**Time together:** Jordan lived for 95 days. Those days were lived within the love of her family in our home.

**Control:** We felt we had all the pertinent information about treatment options versus palliative care, which gave us more control over what our future would look like.

**Peace:** Although we could not save Jordan from her condition, we were able to give her a life rich in love, cuddles, and joy because our providers cared about us enough to let us decide how she would live. I do not live with guilt. I live with the joy of the life she lived because we had such an empowering experience with her providers.



# The future that is

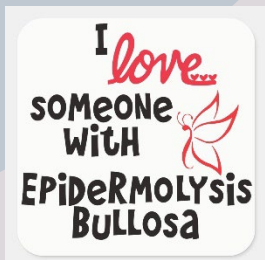


- ✓ HAD TWO BABY GIRLS 14 MONTHS APART
- ✓ LOVE THEM, RESPECT THEIR PERSONHOODS
- ✓ RAISED KATE TO BE A LOVING HUMAN
- ✓ TELLING JORDAN'S STORY
- ✓ LIVING JOYFULLY EVER AFTER

# For more information:

[In-Depth on Epidermolysis Bullosa \(EB\) | debra of America - Types, Symptoms & Treatments](#)

[Junctional Epidermolysis Bullosa – ScienceDirect](#)





# thank you

MANDY LEE

- [mandyleemsn@gmail.com](mailto:mandyleemsn@gmail.com)

# NICU Patient Aid Demo

Angelo Volandes, MD, MPH & Aretha Delight-Davis, MD, JD,  
ACP Decisions



# Wrap Up

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## Next Meeting

- ▶ August 2025 (date TBD)
- ▶ Time: TBD
- ▶ Proposed agenda items:
  - Implementing SDM into practice

# Resources

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- ▶ Washington State Shared Decision Making website
- ▶ Current certified Patient Decision Aids
- ▶ SDM Online Skills Course for Providers
- ▶ National Quality Partners SDM in Healthcare Playbook
- ▶ Bree Collaborative SDM Report and Recommendations for Adoption of SDM