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PARTNERING WITH FAMILIES IN CLINICAL TRIALS:

Real world lessons from mother's journey-from diagnosis to clinical trial, and beyond.

KRISTEN BAUGHER
Mother of Daughter with ALGS
Associate Director Marketing
Mirum Pharmaceutics

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Hello, I’m Kristen

- Wife & Mother: 3 kids ages 21, 17 & 13
- Alagille Syndrome Advocate for my daughter Emmery
- Associate Director of Marketing for Mirum Pharmaceuticals

*The views expressed in this presentation are my own and do not represent or reflect the views of Mirum Pharmaceuticals.



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What best describes the patients you serve?



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In one word, how would you describe the work you do?

inspiration

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1 of 1 responded

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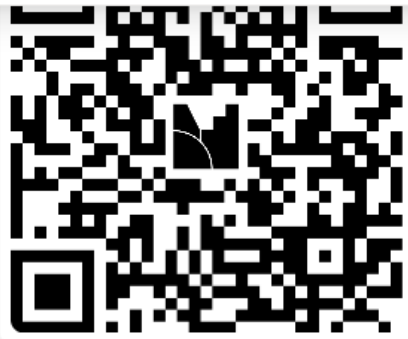
What is your primary goal when interacting with a patient or caregiver?

Responses can be up to 200 characters and will appear here.

You can group responses if you get more than 10.

Turn on voting so people can flag their favorite responses.



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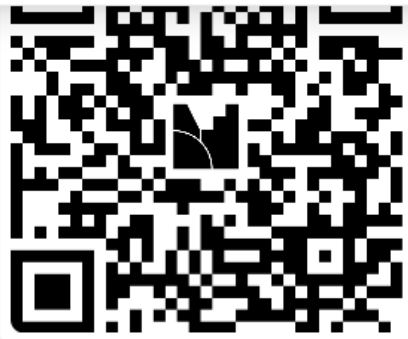

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How often do you get to learn what happened to patients families after the trial ends?

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Often	Sometimes	Rarely	Never
0	0	0	0

Waiting for participants

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What I will share today

- My real-world caregiver journey through diagnosis, drug trial and current day.

- Three lessons from my journey that can help strengthen partnerships with patients and families.

What I Hope You Leave With

- A renewed sense of why your work matters

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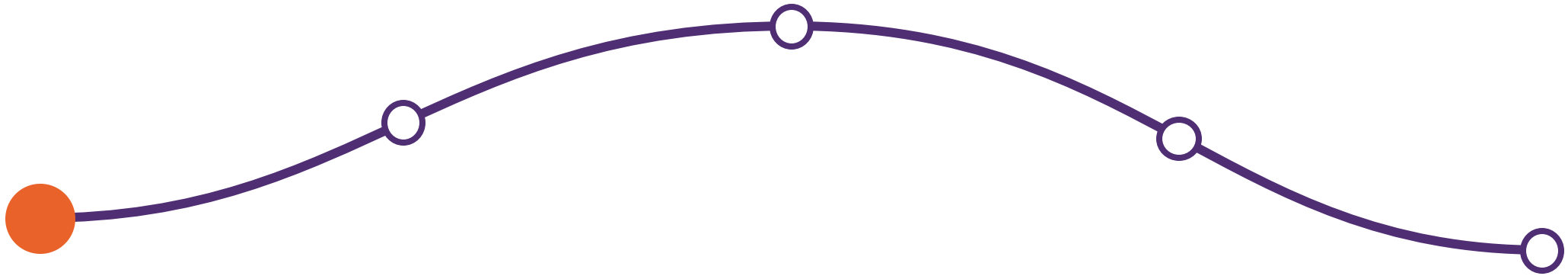
OUR JOURNEY



4/2013

Emmery's Birth & Diagnosis

The starting point of our story.

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Emmery’s Birth





The Call & Diagnosis



Alagille Syndrome



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Navigating a Rare Disease







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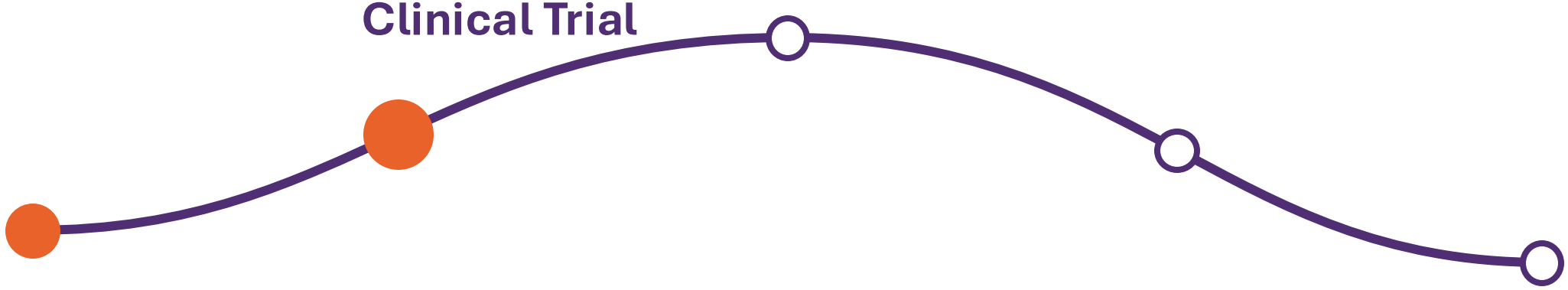
OUR JOURNEY



6/2014

Connection & Clinical Trial

4/2013

Emmery's Birth & Diagnosis

The starting point of our story.

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Connected & Advocacy









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Clinical Trial













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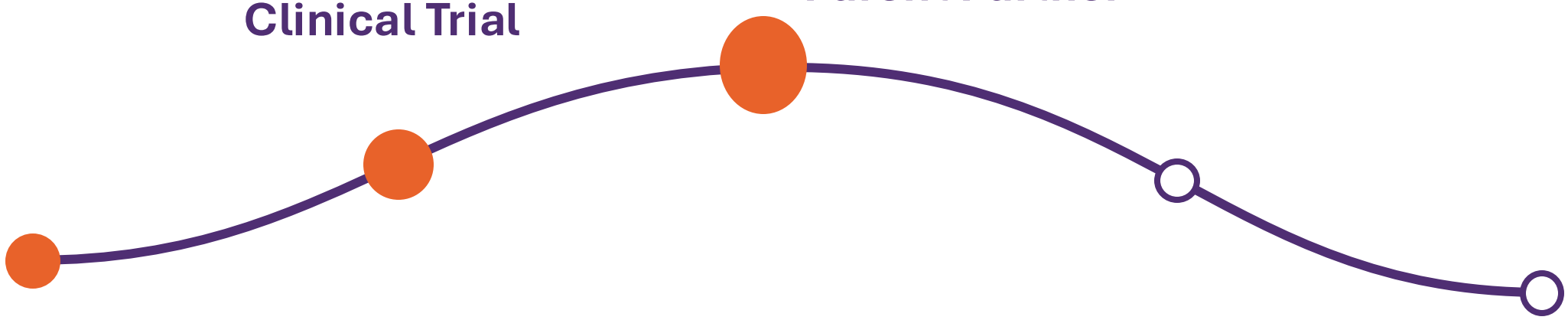
OUR JOURNEY



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Emmery's Birth & Diagnosis

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6/2014

Connection & Clinical Trial

2/2015

Lab Assistant & Parent Partner

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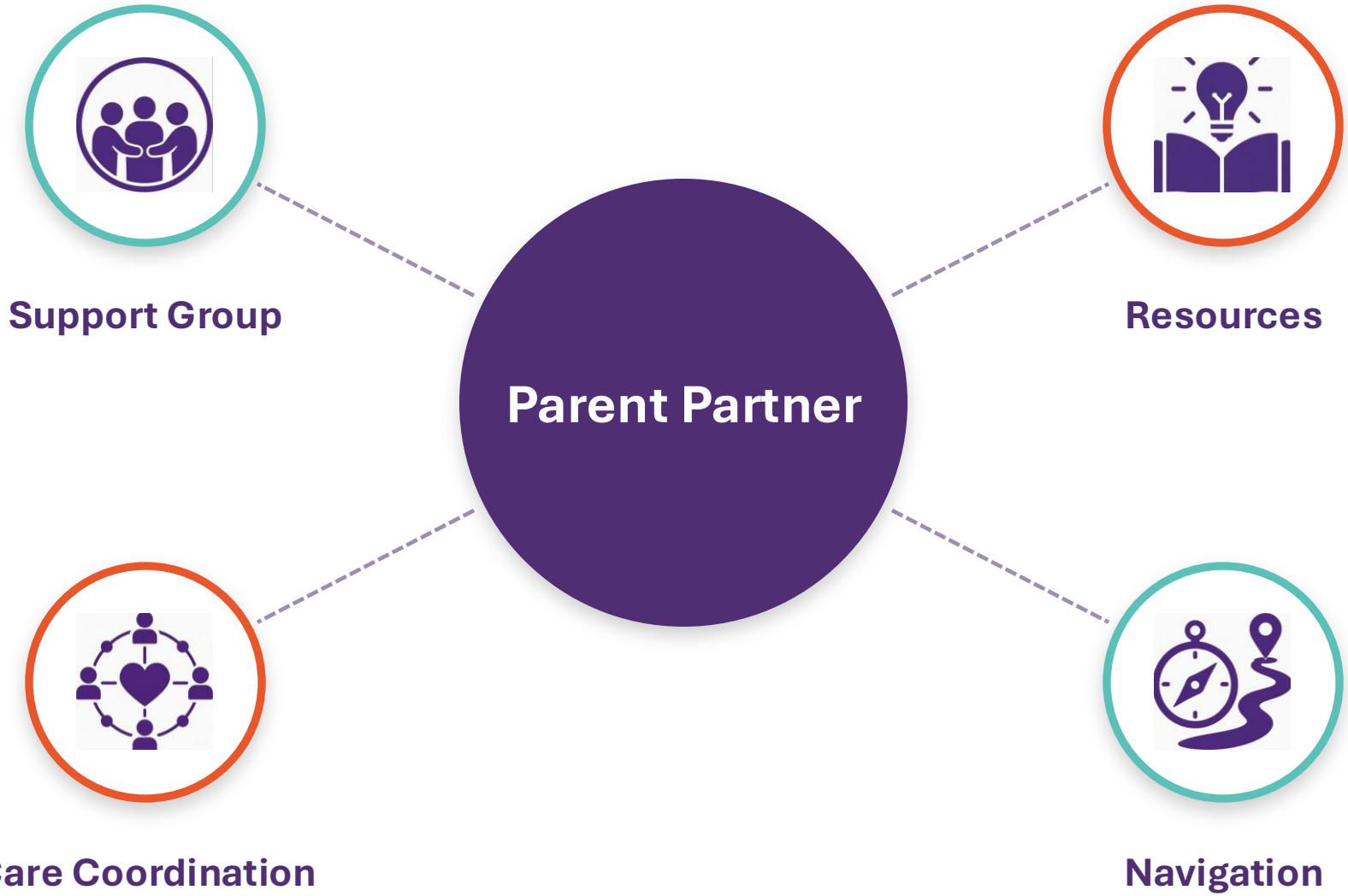

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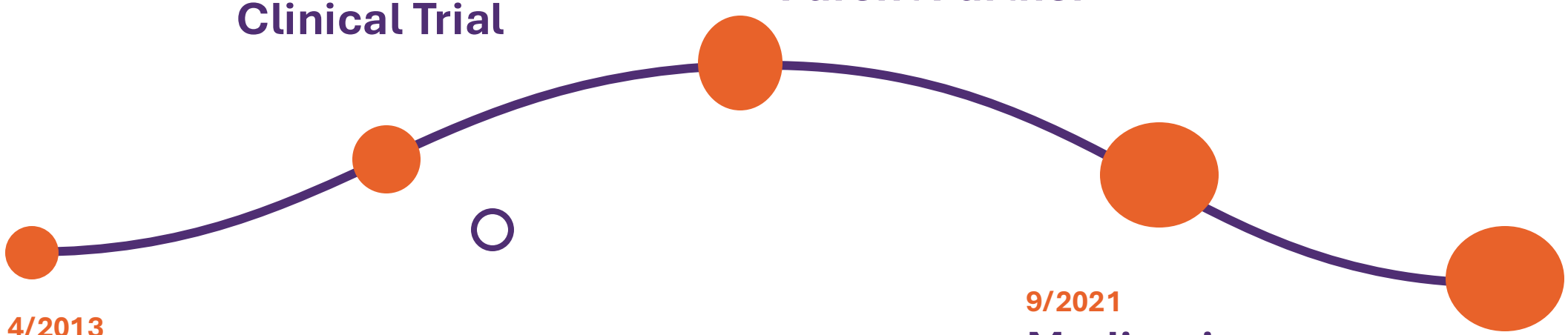

4/2013

Emmery's Birth & Diagnosis

The starting point of our story.

6/2014

Connection & Clinical Trial

2/2015

Lab Assist ant & Parent Partner

9/2021

Medication Approval

Trial Completed





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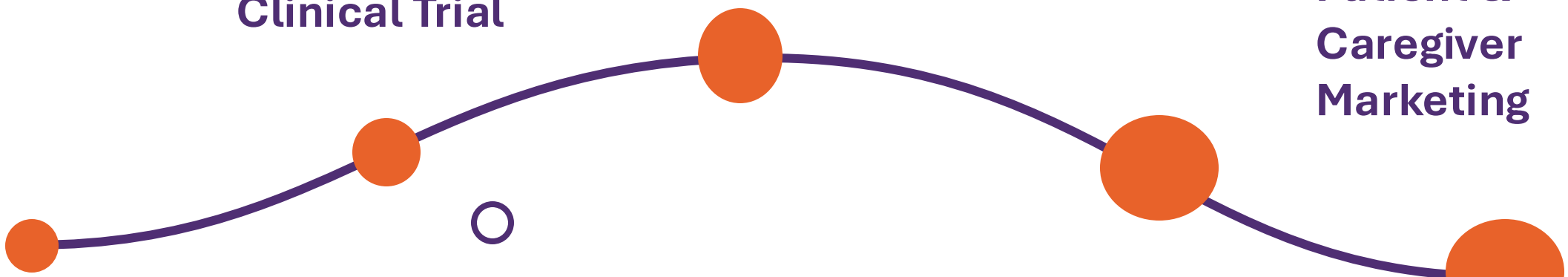
OUR JOURNEY



4/2013
Emmery's Birth & Diagnosis
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6/2014
Connection & Clinical Trial

2/2015
Lab Assist ant & Parent Partner

9/2021
Medication Approval

5/2022
Patient & Caregiver Marketing

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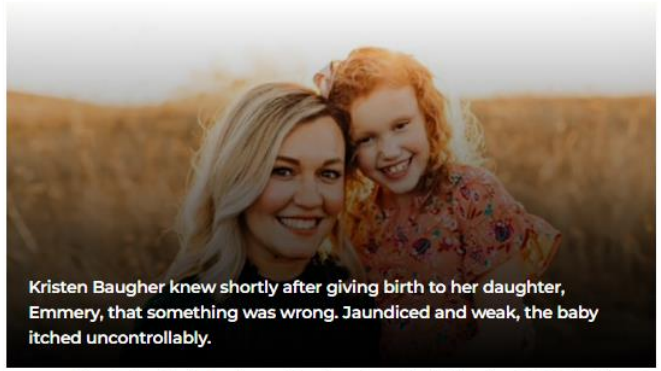
Faced by Patients With Alagille Syndrome

2021



Kristen Baugher knew shortly after giving birth to her daughter, Emmery, that something was wrong. Jaundiced and weak, the baby itched uncontrollably.

Kristen Baugher and her daughter, Emmery, of Salem, Oregon. Emmery, 8, has Alagille syndrome. *Credit: Kelly Kent Photography*



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Emmery & I Today





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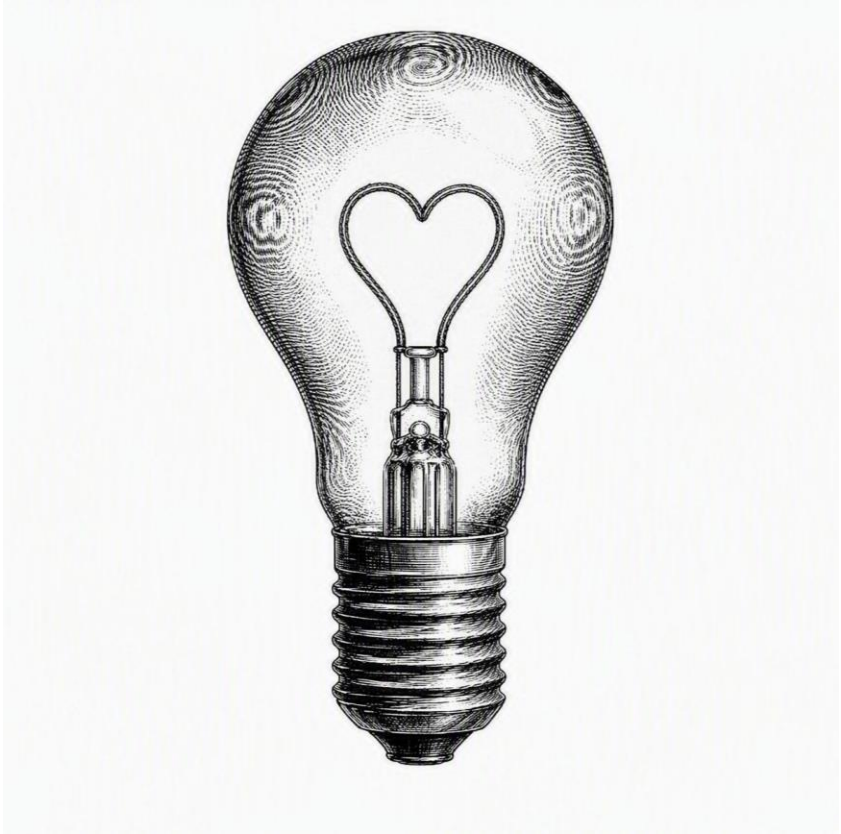
Lessons Learned

Three ways to partner with patients and families to build engagement



Lesson #1 Partnering with Families

Recognize patients and caregivers as equal experts

- You know the study, they know themselves or their child the best.
- Find out what they already know and start there
- Say plainly what is known, what is unknown, and what is still being learned



Share with your neighbor

Choose one prompt to discuss • 2 minutes

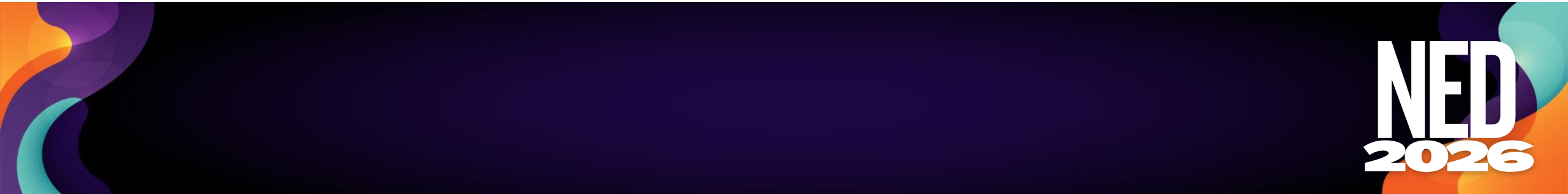
01 ASK

Think of a patient or caregiver you serve. What could you ask that invites them to be the expert, not just the recipient?

OR

02 SHARE

What have you learned that helps patients feel like equal experts?



Lesson #2 Partnering with Families

Listen to Understand, Not to Fix

- Be curious to understand what's beneath the surface.

Listen for what's underneath the words

- Ask what matters most to them right now, then reflect it back.
- Leave room for silence.



Partner exercise

The challenge: listen to understand—not to respond • 60 seconds each

1 SHARE

Partner A

Share something you want to change or do differently—and why.

Examples:
- wake up earlier
- eat more fruits and vegetables
- reduce screen time

2 LISTEN

Partner B

Listen fully. If helpful, ask one open-ended question.

3 REFLECT

Partner B

Reflect back what you heard.

4 SWITCH ROLES

Both partners

Switch roles and repeat the exercise.

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Lesson #3 Partnering with Families

Make them feel known

- Remember the little things
- Know what works for them
- Communicate, “I remember you. You aren’t just another participant”



You may be the only person that understands and cares.

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Three ways to PARTNER with families for stronger engagement.



Treat families as equal experts

Start with what they know. Be clear about knowns, unknowns, and what is still being learned.



Listen to understand…not to fix

Look beneath the words, reflect what matters most, and leave room for silence.



Make every person feel known

Remember the details, adapt to what works for them, and show that you genuinely care.

Thank you



Your Role Matters

Your work reaches far beyond a study, a protocol, or a research center. Every interaction has the power to shape the trajectory of a child's or family's life.

QUESTIONS?

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