



# Sidebysidesibs

Strategic Foundation  
For Partnership

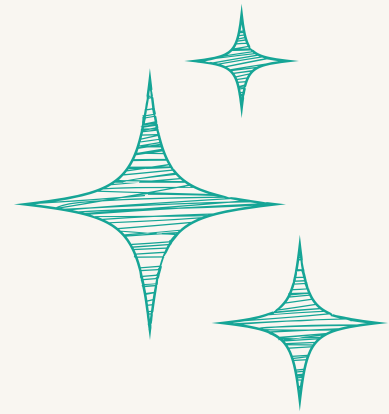
# Mission Statement

To make sibling wellbeing visible and valued by creating accessible, evidence-informed tools that strengthen emotional connection at home and empower families to support every child.

# Vision

A world where siblings of children with disabilities and chronic illnesses feel seen, supported, and celebrated.

We envision families everywhere having simple, sustainable ways to nurture sibling relationships, and a global ecosystem where professionals, foundations, and communities recognise sibling wellbeing as a core part of inclusive care.



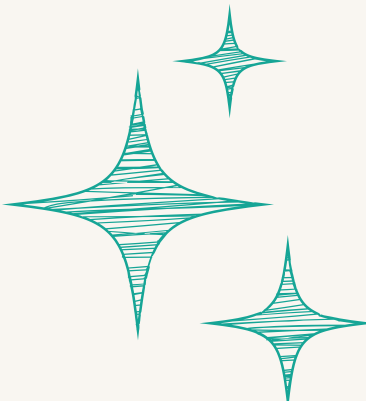
# Organisation Pillars

Pillar I: Awareness


Pillar II: Education  
& Family Capacity

Pillar III: Resource  
development  
(sibling-led)

Pillar IV: Systems  
Influence



# WHY KIF1A, AND WHY NOW



The KIF1A community is uniquely positioned to lead this work.

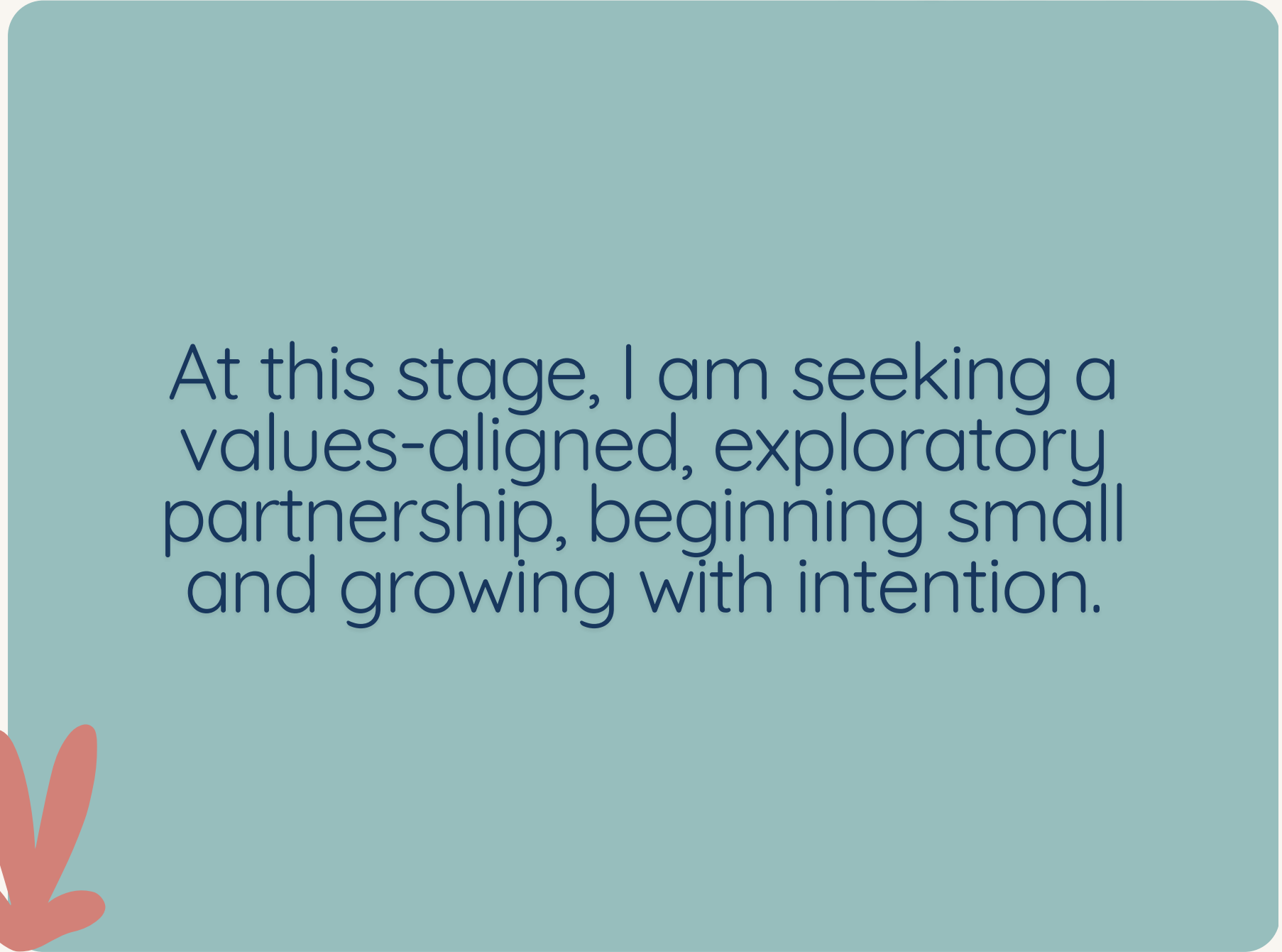
- KIF1A families live the reality of complex care, long journeys, and deep sibling impact.
- The community is global, connected, and values both science and lived experience.
- There is an opportunity to make sibling wellbeing visible early, not years later.



This partnership is not about adding another program. It is about naming what already exists in families and supporting it intentionally.



# Partnership with KIFIA



At this stage, I am seeking a values-aligned, exploratory partnership, beginning small and growing with intention.

**Listen to sibling voices  
for a pilot tool**

**Co-design a simple  
sibling impact  
framework**

**Raise awareness  
together**



# WHAT THIS COULD LOOK LIKE (FIRST PHASE)



- A small, voluntary pilot with interested families
- Collection of parent and sibling reflections
- A shared learning summary for the KIF1A community
- Gentle awareness messaging that says: “Siblings matter too, and here’s how we can support them.”

From there, we can decide together whether deeper collaboration makes sense.




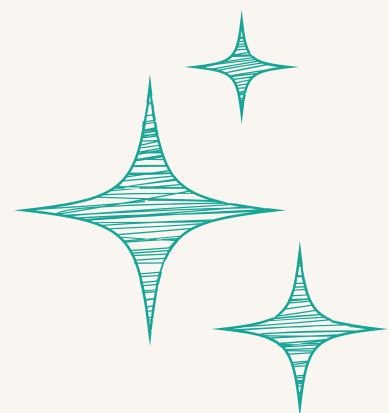


# THE LONGER-TERM POSSIBILITY



If aligned, this partnership could grow into:

- A KIF1A-informed sibling wellbeing model
  - Co-branded resources for families globally
  - Future grant applications grounded in lived experience
  - A foundation for sibling-focused research and evaluation
  - KIF1A helping lead the way in making sibling wellbeing visible across rare disease communities
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# HOW YOU CAN BE PART OF THIS

What We Are Asking From the KIF1A Community

We are seeking:

- Lived experiences from siblings and parents (by filling out separate survey forms)
- Siblings interested in shaping the first pilot
- 2-3 professionals interested in advising on sibling wellbeing
- Ongoing dialogue as we co-design something meaningful



The background features several decorative elements: a teal shape in the top-left with an orange flower; a teal leaf-like shape at the top-center; a pink shape in the top-right with teal dots; a pink shape in the bottom-left with brown leaves; a pink shape in the bottom-right with a yellow leaf; and a cluster of pink dots at the bottom-center.

**Thank You**