



Research: Find the Gaps

If there is a lot of research around your disease - great! This is a good position to be in. But maybe you're in the opposite position. Maybe there is very little research available. This worksheet will help you understand what is currently happening in research and how you can make sure you're not duplicating efforts with other organizations. You're going to create opportunities to end your disease -- we just know it!

1. What is your organization's mission? Always keep your mission top of mind.

2. What do you think is the most promising research happening in your disease right now? What brings you hope? What is most in line with patients? Write down the research that is happening. Which companies are invested in this research?

3. Which organizations in your disease space are already investing or looking to invest in this promising research?

4. After looking at these efforts from other organizations, what is not being addressed? What is missing from the approach? What is the timeline for it? Does it address diversity?

5. For the research you're interested in pursuing - are patients in the discussion and seated at the table? What role do they have? Are they decision makers or honorary positions?

6. What government-sponsored programs exist that are being used by other diseases like your own?

7. Where does that funding come from?

8. Are there congressional leaders you can work with to increase funding next year?

9. Who are the credible partners -- government, institutions, or biopharmaceuticals - that are in this space?

10. Which ones are missing?

11. If you were to create a scientific advisory board, who would you like to include for that group?

12. Back to your mission: Given what you have listed here, what makes the most sense to invest in moving forward?