Understanding the Pediatrician's Role in the "Growing Up Years"

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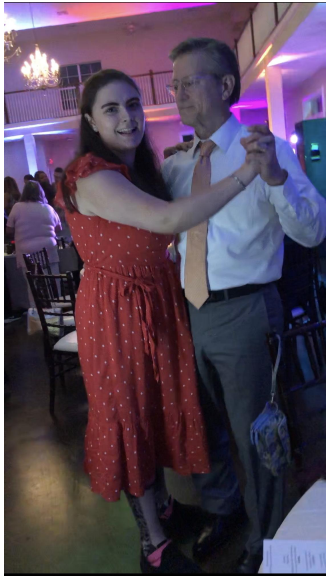
How did you find yourself in the rare disease space?

It found me!






How do you find a pediatrician who is best suited to work with a child with a rare disease?

Are there questions parents can/should ask on the front end, when they are trying to select a good pediatrician?

Respectful listening

- Does your doctor listen to your questions and problems and attempt to address them?
- If he/she is not sure of something will they say so but attempt to find answers?

Time constraints

- How does physician office do scheduling? 10/15 min slots?
- More time? When would that be available?
- Top 2-3 questions ready.

What kind of things can you lean on for your pediatrician?

- Oversight
  - Are we getting good information from various physicians and therapists?
  - Is what we/they are doing helping?
- Coordination of care
  - Do we need to help with the mechanics of getting into the hospital or ED?
  - What about the hospital experience?

https://www.nationwidechildrens.org/about-us/collaboratory/value-based-care/medical-complexity

When do you use a pediatrician vs. specialist in the care of your child? How do they collaborate?

- Specialists have a narrow focus for the things they are most qualified for
- Pluses and Minuses

As a pediatrician how did you process through how to develop a "team of doctors" to care for your rare disease patient?

The Team

- Identify who
- Identify where
- How do we implement the plan?
  - My role as the provider
  - Parent/patient's role

Practical tips that pediatricians should consider when partnering with a rare disease family

- Availability and back-up
  - Needed one or two colleagues with practical understanding of LCHADD
- Trial and error
  - Sometimes hospitals cooperate and sometimes they don’t
- Illness vs metabolic
  - How to navigate when all a patient can communicate is, “I don’t feel right.”

Other practical tips for families, advice, what you wished the "patient knew."

- State the goals.
- What path?
- How available is your pediatrician?
- When they are not available is there adequate back-up?
- When things occasionally don't go well, can you discuss it and find find better care?

How do you know if your pediatrician is a good fit to help you monitor your FAOD/ rare disease?