

# Patient Centered Care:

## How to build a medical care team

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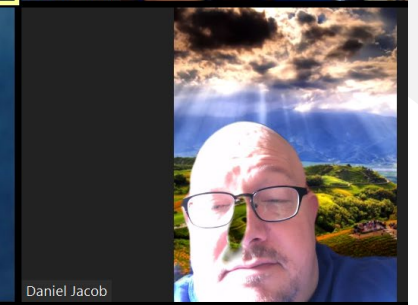
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## Disclosure of Conflicts of Interest

- Grant funding from Amicus Therapeutics; Genzyme, a Sanofi Company; & Shire/Takeda.
- Research coordinator for industry sponsored studies from Amicus Therapeutics; BioMarin; Sanofi-Genzyme, Idorsia; Protalix; & Shire/Takeda.
- Serve on the Fabry Registry NA Board of Advisors
- Serve on the KrabbeConnect Board
- Honoraria/consulting: Amicus, Shire, and Sanofi-Genzyme
- Co-Founder, ThinkGenetic, Inc.

# How Did I Arrive Here?



# Acute vs. Chronic

Across the spectrum, Krabbe disease involves chronic, life-impacting medical issues interspersed with acute events. Those living with the conditions, and the health care providers who work with them, need a long-term plan that addresses both situations.



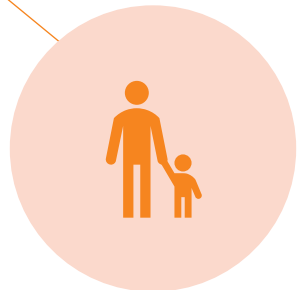
# In order to take a long-term view, some key things are required



A care plan for monitoring and treatment designed using knowledge and evidence to lead to the best possible outcome.



A Health care provider (HCP) to implement and oversee the plan



Patients/parents/caregivers to let the HCPs know what is and is not working with the plan



HCP/patients working together who can quickly alter the plan to fit new pieces of the situation

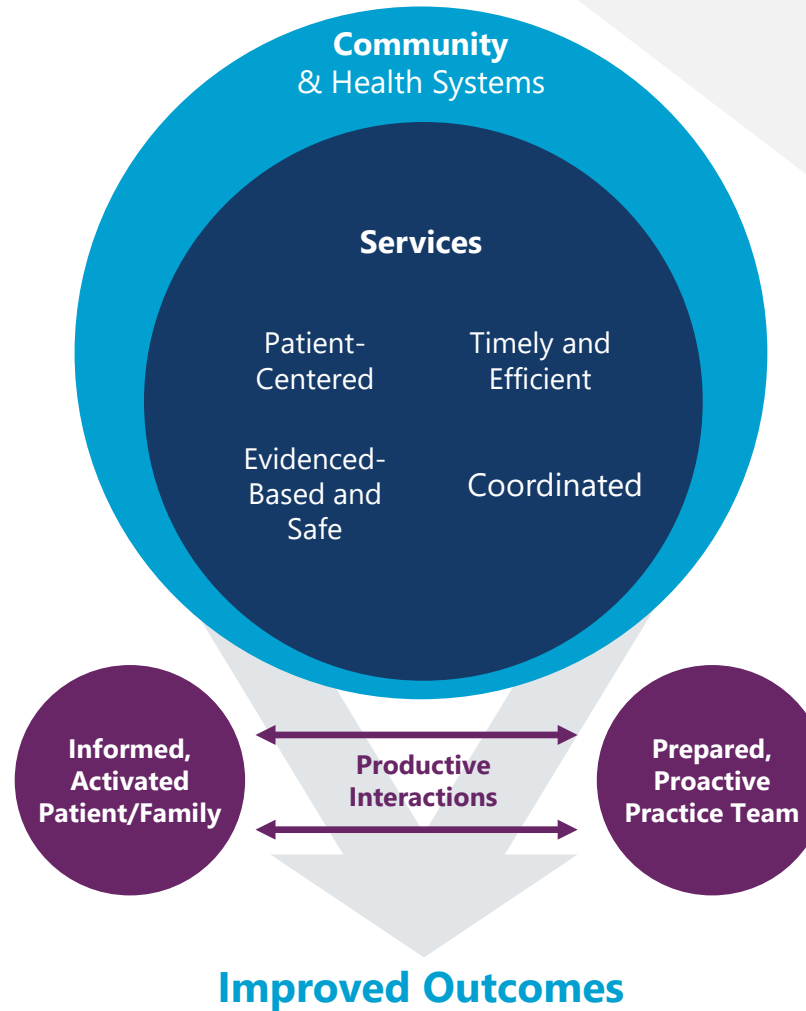


# Who has seen this done well?



# How?

- An engaged medical care team working together in partnership with patients, families, and caregivers
- Key features:
  - Patient-centered care
  - Better communication
  - Improved health outcomes



**References:** 1. US Department of Health and Human Services. Agency for Healthcare Research and Quality. Practice Facilitation Handbook. Module 16. Introduction to the Care Model [www.ahrq.gov](http://www.ahrq.gov). 2. Coleman K, Austin B, Brach C, et al. Evidence on the Chronic Care Model in the new millennium. Health Aff (Millwood) 2009;28(1):75-85.

# How is this different?

## Standard

- Little CENTRALIZED, coordinated care
- POOR COMMUNICATION between healthcare professionals on team.
- MISSING records and information
- DUPLICATE testing
- DISCONNECT: between primary care practices and specialized doctors and hospitals.



## Patient Centered

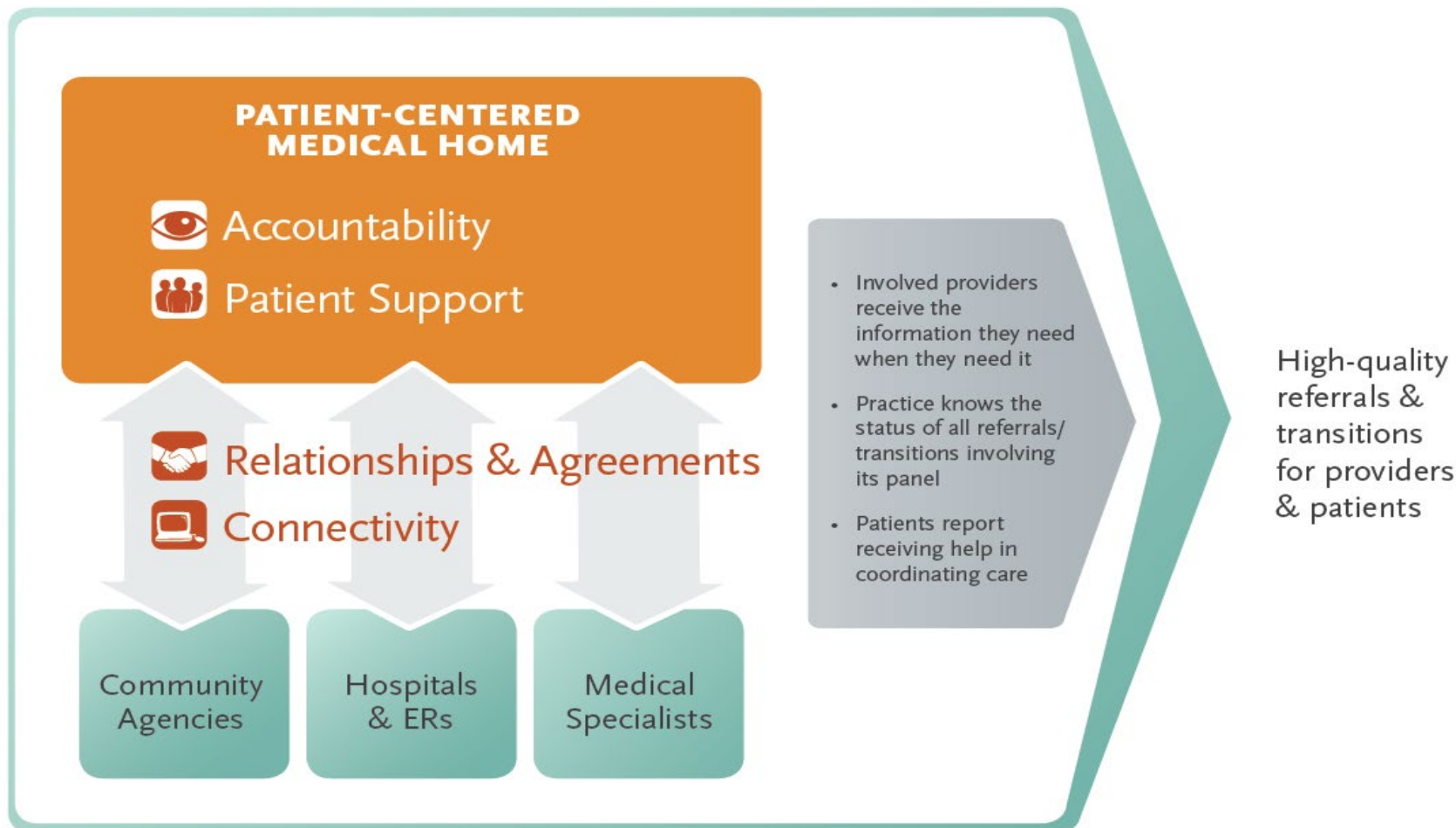
- A MEDICAL HOMEBASE: One main point of contact "Your Quarterback"
- A TEAM GAME PLAN with the patient at the center
- Increased COMMUNICATION regarding treatment options, testing, changes in care, appointments, and next steps.





# Foundation of Four Key Concepts

*Patient Support, Doctor-Patient Relationships, Accountability, and Connectivity  
Between All Aspects of Medical Care*



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# How You Benefit

## *Right Care, Right Time, Right Place*

Example of a Care Model in Action:

**PROBLEM:** Ongoing Weight Loss.

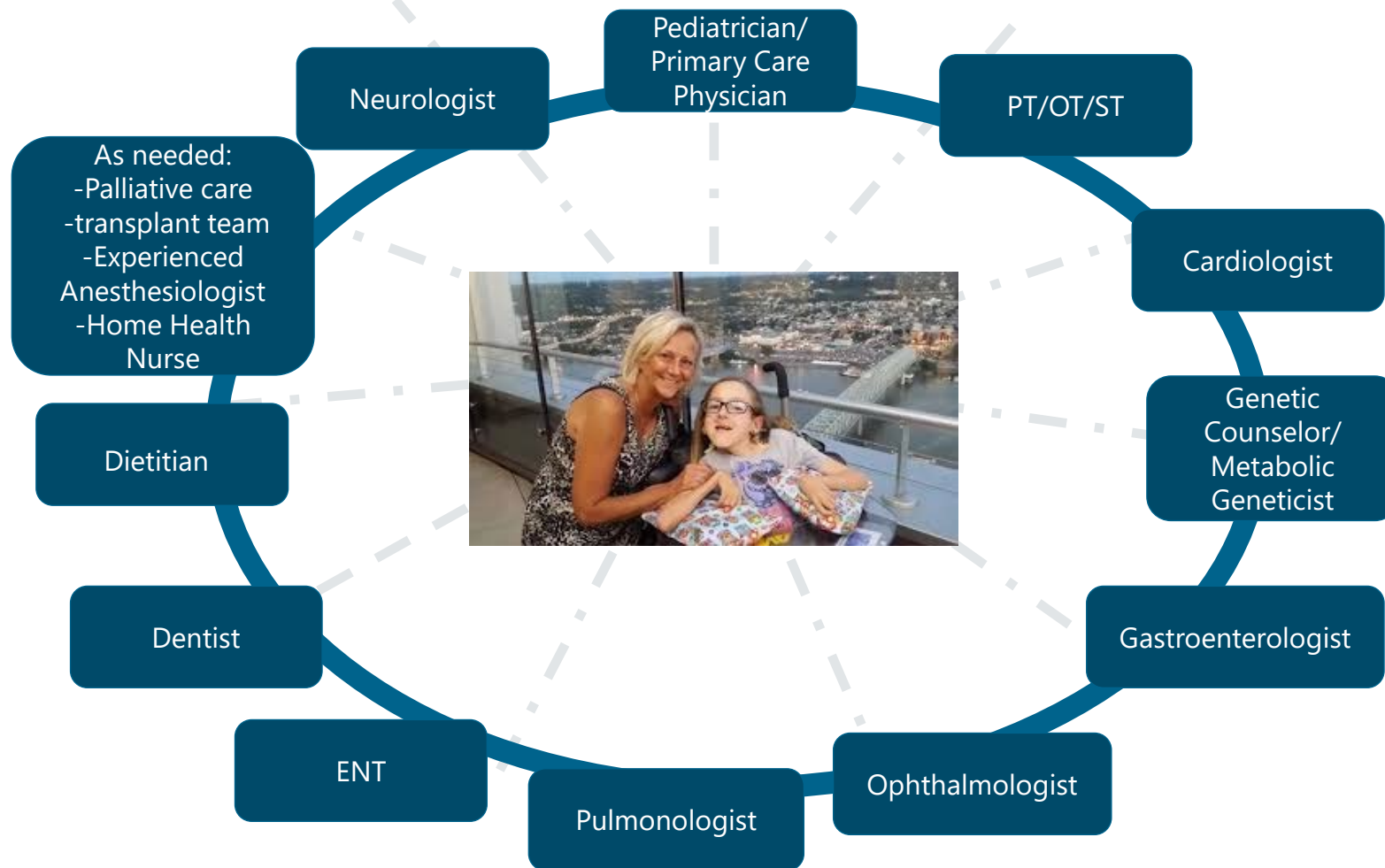
- Patient visit to pediatrician/primary care doctor
- Primary doctor refers patient to GI specialist
- Doctor's team makes sure appointment is made and confirmed
- Insurance and any out-of-pocket costs discussed with patient
- Clinical information (medical records) communicated to specialist.
- Patient goes to GI specialist appointment
- Next steps, test results, and treatments conveyed to primary doctor/patient

A high-functioning medical system of care provides patients with access to the 'right care at the right time in the right place'. <sup>1</sup>

# Who's on the Team?

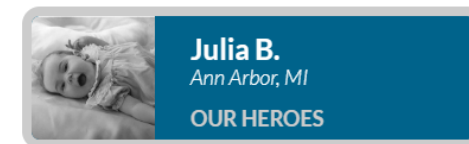


# A Sampling of Health Care Providers (HCPs) in a Team for Krabbe disease



# How Do You Assemble Your Own Care Model Team?

<b>Step 1</b>	<p>Take a close look at your current doctors to see if they would be a good fit for your Care team or are already performing this function.</p> <p>Consider consulting with an existing Leukodystrophy/Krabbe Treatment Center to lead or work with our team.</p>
<b>Step 2</b>	<p>Talk to your chosen healthcare providers about your expectations for someone joining your care team.</p>
<b>Step 3</b>	<p>Educate your chosen care team about Krabbe disease as needed</p>
<b>Step 4</b>	<p>Work with your care team leader (Quarterback) to coordinate care with your specialists.</p>



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## Connect with a Clinical Expert

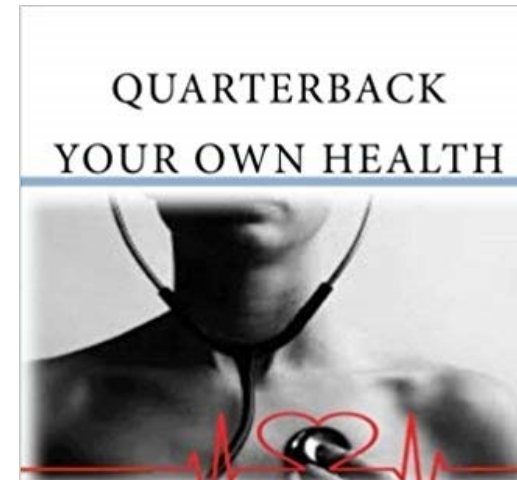
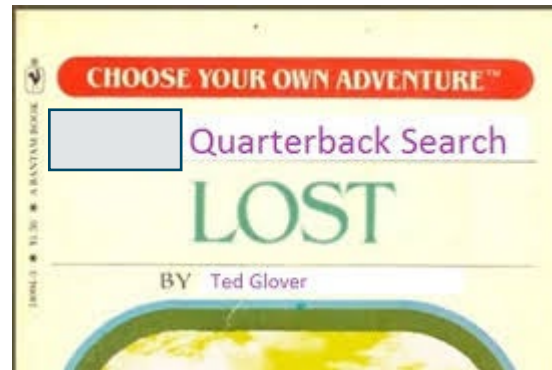
Once your neurologist suspects or confirms your diagnosis as Krabbe disease, it's important to get connected to the right experts. Due to the complexity of this rare disease, it's likely your care team has *never* encountered another patient with this condition. It's imperative that your family member receives the most innovative options for treatment and management of the disease.

The following have been identified as leaders in the care and clinical management of Krabbe disease. As a rare disease organization, we are grateful for each of the below experts whom are well known around the world for their program and can meet the extensive medical needs of patients with Krabbe disease.



# No Quarterback?

- Keep Looking
- Consider “Telemedicine” Models with Centers familiar with your condition
- You may have to fill in for a bit...



# What makes a good HCP in KD

- Long term care provider
- Active Listener
- Able to be contacted
- Patience
- Follow through
- Willingness to be a life-long learner
- Straight-forward and honest about the good and the bad, the known and the unknown



# What makes a good patient?



*"Well, this is a very impressive résumé, young man. I think you're going to make a fine patient."*

# Helping you become a good teammate helps your healthcare providers be better teammates as well

## About a Nurse



*"I realize nurse Anne is hard to work with, but hiding from her isn't the answer."*

# Stay Current With Your Medical Care



Learn about the condition affecting your family



Know the specific health issues and treatment plan.



Be active in your support group of choice



Ask for copies (digital or paper) of medical records.



Sign up for medical patient portals

# Engage With Your Care Team

- Bring a list of questions to each appointment
- Communicate in regular intervals
- Be open and honest about any symptoms
- Do not ignore health issues
- Follow treatment recommendations or discuss alternatives
- Make sure you know who to call to discuss specific health issues
- Be appreciative!



# Help HCPs to Help You

- Learn about Krabbe disease
- Recognize that you are the expert on you or your loved one
- Know your specific health issues and follow your management/treatment plan or discuss parts that do not work prior to stopping
- Be active in an KD support group
- Ask for copies (digital or paper) of medical records
- Sign up for medical patient portals

# Important Questions When Visiting a Specialist

- 1. Who am I seeing?
- 2. Why am I seeing them?
- 3. How do I get there?
- 4. What questions do I want answered?
- 5. Do I need tests or procedures before the visit?
- 6. What do I need to do to be ready for the visit?
  - a. Should I bring my medication list?
  - b. Should I bring records or X-rays?
  - c. Should I fast or change my usual eating?
- 7. Will my insurance cover the visit?
- 8. Will there be co-pays or other charges?
- 9. Do I know who to call if I have trouble with the referral?
- 10. What can I expect after the visit?
  - a. Who will call me with results?
  - b. Who will tell me what to expect next?
  - b. Do I need to check in with my primary care team?
  - c. Will I see the specialist again?
- 11. Is there anything else I should know about the visit?

# Prepare Ahead for Emergency Situations



- Learn what constitutes a medical emergency
- Consider asking your Care Team for an Emergency Room (ED) letter that includes basic information about KD and how to contact your Care Team
- Have a written list of all medications/supplements that are being taking and their dosages

## **PRACTICAL TIP:**

Ask to sign a medical records release to have the ability to share your medical information with other members of your care team

# Take Care of YOU! (Caregivers)

- Ask for help if you need it
- Connect with others living with KD
- Learn more about respite care
- Don't forget about you

70 % of surveyed caregivers said they aren't keeping up with their own medical appointments

>60% admit to "poor eating habits."

# Summary

Krabbe disease is a chronic disease and benefits from long-term health goal planning



Working with healthcare providers as part of team can improve the care of individuals living with Krabbe disease



Patients and caregivers can advocate for better health by:

- Staying engaged
- Increasing and improving communications
- Learning about the disease
- Asking questions
- Following their management/treatment plan and asking for adjustment as needed

# Helpful Resources

- **KrabbeConnect** <https://krabbeconnect.org/>
- **Hunters Hope** <https://www.huntershope.org/>
- **ThinkGenetic.com** (Patient focused information)  
<https://www.thinkgenetic.com/diseases/krabbe-disease/>
- **GeneReviews-** (Doctor focused but helpful)  
<https://www.ncbi.nlm.nih.gov/books/NBK1238/>



# Team of Emory LSD Genetic Counselor and Clinical Trial Quarterbacks



# Questions?





# Thank You.



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