

KrabbeConnect Patient Journey and Resource Map

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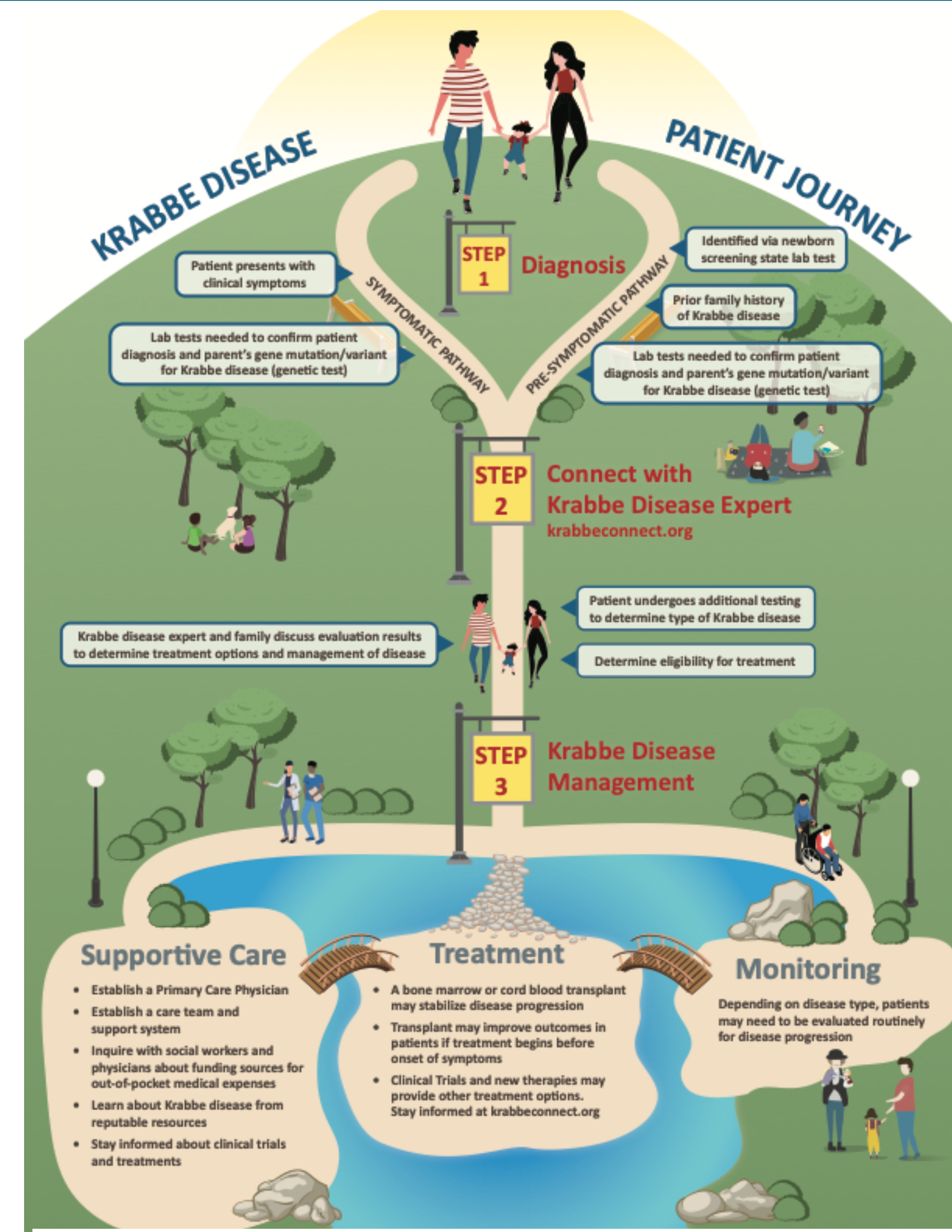
Background

- Krabbe disease (KD) is a devastating neurodegenerative genetic disease caused by pathogenic variants in the *GALC* gene.
- A population of parents with children diagnosed with KD through newborn screening are seeking guidance about KD, next steps, monitoring, and (in infantile-onset cases) making rapid informed decisions about hematopoietic stem cell transplantation (HSCT).
- The goal of this project was development of a patient-friendly KD roadmap designed to provide information, education, and direction to parents in collaboration with their healthcare providers.

Methods

- KrabbeConnect and TOPCAT BIO collaborated to develop a graphic resource utilizing existing literature designed to address informational gaps identified by parents and caregivers of patients living with KD and other community stakeholders including healthcare providers and advocacy representatives.
- This resource was then evaluated by a core group of parents, caregivers, and healthcare providers to determine utility and usefulness in addressing the existing informational gaps in KD.

Results



Discussion

- The deluge of information provided to parents upon the diagnosis of a genetic disorder such as KD can be overwhelming and make it difficult to prioritize decisions and next steps.
- The development of a simple roadmap with easy-to-follow steps supports decision making and closes several of the identified informational gaps.
- This resource helps families and the healthcare providers to develop individualized treatment and care plans.

Conclusions

- KrabbeConnect has developed a user-friendly, patient journey map to help families and medical professionals understand decision points, next steps, and available resources to support them as they make timely informed decisions that are right for their loved one.
- To obtain copies of these KrabbeConnect maps, visit KrabbeConnect.org.

Acknowledgements

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