

## ROHHAD Families,

Here at the Center for Autonomic Medicine in Pediatrics, we continually strive to provide the best possible care, and produce the best possible outcomes, for all of our patients. In the ever-advancing field of technology, incredible devices are being made with the potential to revolutionize how we monitor and collect data on our patients battling ROHHAD. **Hexoskin Smart Garments** are comfortable pieces of clothing with embedded sensors for precise and continuous cardiac, respiratory, activity, and sleep monitoring. We are hoping to send Hexoskin devices to patients to wear at home or during everyday activities so we can establish biomarkers, or indications of normal or abnormal processes taking place in the body, while at home.



## What is our goal?

Our goal with this project is to enhance our ability to predict breathing needs of ROHHAD patients. Since ventilators and/or pacers used in ROHHAD patients have settings set by hand, they need to be changed all the time based on what your child is doing. By using Hexoskin we hope to develop an algorithm, sort of like a recipe or instructions for a computer, that can predict breathing needs then adjust vent/pacer settings automatically to fill those needs.

## What does participation involve?

If your family decides to participate, our study team will have your child wear the Hexoskin device during their time visiting CAMP, and we may send the device home with you for up to a week of continuous data collection. These garments are form fitting, so your child may feel some discomfort while participating. If any discomfort is noted the garments can be adjusted or, ultimately, removed at any time. A study team member will go over all of the necessary instructions for use and returning the device before sending it home with you.

**Thank you!** We appreciate your interest in this project. If you have any questions in the meantime you can contact **CAMP** at [CAMP@luriechildrens.org](mailto:CAMP@luriechildrens.org), or ask the CAMP staff to reach out and someone from our research can come answer your questions in person!