

Center for Autonomic Medicine in Pediatrics (CAMP)

A Resource Guide for our Families



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Welcome to Ann & Robert H. Lurie Children's Hospital of Chicago!

Our team is excited to host you for your upcoming visit. We hope this guide will assist you in planning and preparation, but please feel free to reach out to us at 312-227-4000 with any questions.



Table of Contents

1. [What is CAMP?](#)
2. [Specific Conditions Among Children Referred for Evaluation](#)
3. [How do I get to CAMP?](#)
4. [Specialists and the Care Team](#)
5. [Consulting, Collaborating, and Supporting Teams](#)
6. [Inpatient Care](#)
7. [What to Expect During Inpatient CAMP Admission](#)
 - a. [What You May Want to Bring to CAMP](#)
 - b. [What Follow-up to Expect After a CAMP Stay](#)
 - c. [Questions You May Want to Ask Your CAMP Provider During the Inpatient Stay](#)
8. [Common Inpatient CAMP Health Screening Tests and Assessments](#)
9. [Autonomic Testing](#)
 - a. [Pupillometry Test](#)
 - b. [Orthostatic Head-Up Tilt \(HUT\) Test](#)
 - c. [Heart Rate Deep Breathing \(HRDB\) Test](#)
 - d. [Valsalva Maneuver Test](#)
 - e. [Thermoregulatory Sweat Test \(TST\)](#)
 - f. [Quantitative Sudomotor Axon Reflex Test \(Q Sweat Test\)](#)
10. [Common Inpatient Testing: Autonomic Tests](#)
 - a. [Orthostatic Head-Up Tilt \(HUT\) Test](#)
 - b. [Pupillometry Test](#)
 - c. [Peripheral Skin Temperature Testing](#)
 - d. [Exogenous Ventilatory Gas Challenges](#)
 - e. [Inpatient Autonomic Day Study](#)
 - f. [Inpatient Autonomic Night Study](#)

What is CAMP?

- CAMP stands for the **Center for Autonomic Medicine in Pediatrics**, which is in the division of Autonomic Medicine at Ann & Robert H. Lurie Children's Hospital of Chicago. It is an interdisciplinary program for infants, children and young adults with conditions that affect their autonomic nervous system (ANS). The ANS controls the body's "automatic" functions, such as:
 - Breathing
 - Temperature regulation
 - How your heart, blood and brain work together
 - How food moves through your body
 - How your eyes respond to light
- Learn about our unique and world-renowned center in this overview that provides information about inpatient stays and outpatient testing.
<https://vimeo.com/84871667>

Specific Conditions Among Children Referred for Evaluation

Our physicians are at the forefront of ANS treatment advances, making sure they provide our patients with the most up to date testing and treatment options possible. Several examples of the conditions we treat include:

- [Congenital Central Hypoventilation Syndrome \(CCHS\)](#)
- [Rapid-onset Obesity with Hypothalamic Dysfunction Hypoventilation & Autonomic Dysregulation \(ROHHAD\)](#)
- [Postural Orthostatic Tachycardia Syndrome \(POTS\)](#)
- [Neuromuscular Disorders](#)
- [Neuropathy](#)

Research is an integrated component of the clinical CAMP experience. Our clinical and research teams work together daily to ultimately improve care delivered in the inpatient and outpatient setting, as well as at home. Nearly all patients seen in CAMP will meet a member of our research team and be asked if they would like to participate in our ongoing studies.

[Back to Table of Contents](#)

How do I get to CAMP?

Travelling to Lurie Children's Hospital --

To help prepare for your visit to Lurie Children's, please use the travel resources listed below.

- **Air Travel**

Traveling with a child who has complex airway care (such as a tracheostomy or ventilator) can be stressful. Consider adding additional time to get to the airport and navigate TSA.

Consider contacting TSA for support before you travel (please see the image on the right of the blue card).

- [Directions](#)

Find out how to get to the main hospital. (Map on the next page)

- [Parking & Transportation Tips](#)

For those driving or taking public transportation to the main hospital, we've provided some helpful tips for you to keep in mind when preparing for your visit. (Map on the next page)



TSA Contact Information

2nd floor check-in desk



Check-In Outpatient

You will take the elevator or escalator up to 2nd floor. Once you receive a badge at the check-in round desk (pictured to the left), you will take an elevator to the 3rd floor. There, you will check in at the desk right off the elevators and wait for someone from CAMP to call your name.

Inpatient

Check in at the security desk on the first floor by the Superior Street hospital entrance. You will then be escorted to the HCID for COVID testing. If COVID testing is not required, please follow the **outpatient** check-in instructions.

- [Lodging & Accommodations](#)

View a list of hotels and other lodging options near the main hospital. Be sure to mention that your child will be admitted to the hospital as several hotels offer discounts for Lurie families.

- [Amenities & Nearby Services](#)

There is a variety of food and dining options in the area as well as other local services.

- [Family & Community Destinations](#)

Community destinations such as Cafés, Gardens, Chapels, and fun places for children to visit within Lurie Children's.



[Back to Table of Contents](#)

Specialists



Debra E. Weese-Mayer, MD, provides leadership as Chief of the Center for Autonomic Medicine in Pediatrics and Professor of Pediatrics at Northwestern University Feinberg School of Medicine. Dr. Weese-Mayer is recognized internationally for her clinical care and translational research study of children with disorders of respiratory control and autonomic regulation, and as a pioneer in developing the newly emerging discipline of Pediatric Autonomic Medicine.



Susan Slattery, MD, HSOR, is an attending physician at the Center for Autonomic Medicine in Pediatrics and Assistant Professor of Pediatrics - Neonatology at Northwestern University Feinberg School of Medicine. Her interests include control of breathing disorders like CCHS and ROHHAD as well as physiologic data analytics in high-risk children and premature neonates.



Ilya Khaytin, MD, PhD, is an attending physician at the Center for Autonomic Medicine in Pediatrics and in Pulmonary and Sleep Medicine, as well as Assistant Professor of Pediatrics at Northwestern University Feinberg School of Medicine. His interests include control of breathing disorders like CCHS and ROHHAD as well as obstructive sleep apnea, non-invasive positive airway pressure, excessive sleepiness, behavioral insomnia, narcolepsy, and sleep in children with neurologic disorders.

Meet the members of the CAMP team!



Hannah Alvarez

Autonomic Medicine
Specialist



Cindy Brogadir

Autonomic Medicine Specialist

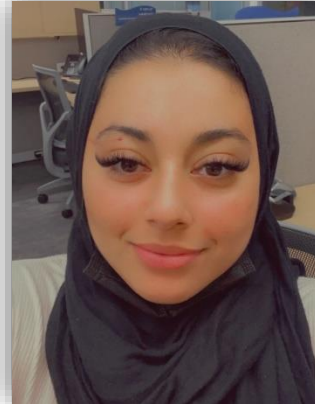


Right: **Tara Chung**

Autonomic Medicine
Specialist

Left: **Beth Lappin**

Autonomic Medicine
Specialist



Allaa Fadi-Alla

Clinical Research Coordinator 2



Narayanan Krishnamurthi

Physiological Data Scientist

(CAMP team members continued)



Casey Rand

Clinical Research Manager



Katherine Reed

Lead Autonomic Medicine
Specialist



Erin Smith

Autonomic Medicine
Specialist



Tracey Stewart

Manager and Autonomic
Medicine Specialist



Leticia Washington

Sr. Administrative Assistant –
Clinical and Academic

Consulting and Collaborating Medical Teams at Lurie Children's Hospital

[Back to Table of Contents](#)

Along with the family and referring physician, CAMP integrates the expertise of specialists from across the hospital to thoroughly evaluate each child and develop a treatment plan that is specific to each child's needs. CAMP's collaborating divisions include:

- [Cardiology](#) (including [Electrophysiology team](#))
- [Gastroenterology](#) (including the [Intestinal Rehabilitation team](#))
- [Neuropsychology](#)
- [Nutrition Team](#)
- [Oncology](#)
- [Otolaryngology](#) (including the [Aerodigestive team](#))
- [Pediatric Surgery](#) (including [Hirschsprung team](#))
- [Physical/Occupational Therapy](#)
- [Speech Therapy](#)

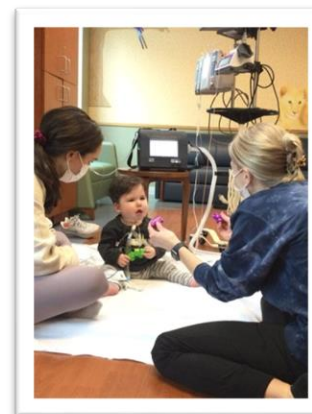
Additional Members of Lurie Children's Hospital Care Team

CAMP will work with you to determine the need for/availability of the following services and help navigate the referral process, if necessary.

*** Please keep in mind – all services may not always be available in all areas across the hospital ***

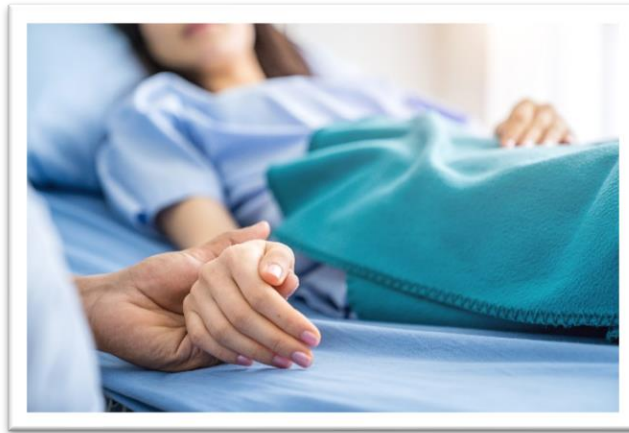
- [Snow City](#) – An award-winning, independent nonprofit organization that educates and inspires children in hospitals through the arts.
- [Art Therapist](#) – In between testing and a long day at CAMP, an Art Therapist can visit your child. Art is a natural language for children. It helps them process and express their thoughts and feelings. Art therapists are clinically trained professionals who use a variety of art materials to help improve the physical and emotional well-being of patients and families.
- [Social Worker](#) – Lurie Children's Hospital has specially trained and certified social workers who collaborate with your child's medical team to make sure your child has the best hospital stay possible. Social workers support you and your family by helping you to understand your child's illness, solve problems that result from your child's illness, find community and hospital resources, and [access additional financial resources](#) when available and appropriate.
- Case Management – A case manager is available to assist with medical care coordination.

- [Child Life Specialist](#) – A child life specialist is a trained professional who helps children and their families understand and normalize the hospital environment. They are skilled at providing developmentally appropriate support, preparation and therapeutic play opportunities to decrease anxieties associated with being in the hospital. Sibling support is also offered to help siblings understand what is happening, help them work through their feelings and answer their questions about the hospital experience.
- [Interpreters](#) – All patients and families have the right to have complete information regarding diagnosis, prognosis and treatment in a language they understand. Services include:
 - In-person Spanish language interpreting from 7 a.m. to midnight, seven days a week
 - Up to 40 other in-person language interpreters, including Polish, Arabic, Chinese, Bosnian/Croatian, Russian, Serbian and Vietnamese
 - In-person sign language interpretation
 - Phone-based interpretation is available at all times for more than 180 languages
- [Music Therapist](#) – Music therapists are uniquely trained to harness the therapeutic qualities of music to use with children, including surgical patients and babies. The music therapists at Lurie Children's Hospital use techniques like song writing, composition, improvisation, music-based play, and listening to music to help uplift the child's mood and offer an outlet for their feelings.
- [Education Team](#) – Lurie Children's Hospital offers various education programs to patients and their siblings to make sure their stay at the hospital doesn't disrupt your child's learning. Many of our programs are led by teachers with years of experience in the education system.
- [Chaplain](#)- Lurie Children's Hospital Chaplains provide emotional and spiritual care to people of all faith traditions, as well as those with no religious affiliation. They are professionally trained and qualified to provide emotional and spiritual support for your family in a hospital setting and offer resources such as Shabbat candles, Kosher foods and pantry, prayer rugs, scriptures and sacred books.



Support Services

- [How to help siblings cope](#) – A child's illness can affect the entire family. We offer advice on ways to help your family cope.
- [Managing your child's pain](#) – Pain management is a very important part of your child's care. We work hard to help your child feel better and use many different strategies to relieve pain. Communicate with your team, and let us know what approaches may have worked well to manage your child's pain



- [ParentWISE](#) – ParentWISE volunteers are parents who know first-hand what it is like to care for a child with specialized needs. They are available for one-on-one connections via phone to offer support in multiple ways during admission, before a procedure or throughout outpatient treatment.
- [PeerWISE](#) – Similar to ParentWISE, PeerWISE volunteers are former patients who can talk to and mentor current teen patients or their parents. As patients who have already walked this path, PeerWISE volunteers can give current patients and their families valuable insights into the treatment process.

[Back to Table of Contents](#)

Inpatient Care

The inpatient service is central to CAMP. The inpatient admissions are most commonly for children with central breathing disorders including [congenital central hypoventilation syndrome \(CCHS\)](#) or [rapid-onset obesity with hypothalamic dysfunction, hypoventilation and autonomic dysregulation \(ROHHAD\)](#). CAMP is a unique patient experience. In this program, your child won't be one of many in a group of CAMP patients. They will receive individual attention and customized treatment.

Typically, CAMP admissions include four days and four nights with extensive monitoring and recording of your child's functioning (physiologic recording) while they are awake and asleep. There is an emphasis on obtaining assessments during activities of everyday life in which your child is awake, such as quiet restful activity, schoolwork and reading, and varied levels of physical exertion based on your child's activity levels and preferences.

For example, we observe and manage the treatments of those who may enjoy activities such as playing sports, playing musical instruments, and dancing. Many other tests from other hospital divisions (specific to each child's needs) are performed as well. All are aimed to improve the clinical care and management of your child, to optimize their short- and long-term outcomes and decrease the overall disease burden for your child and family.

- Common Components of the Inpatient Stay
 - Autonomic Night Study
 - Autonomic Daytime Study
 - Health Screening:
 1. Abdominal Radiograph
 2. Abdominal Ultrasound
 3. Chest Radiograph
 4. Electrocardiogram
 5. Echocardiogram
 6. Holter Monitoring
 7. Laboratory Blood and Urine Tests (most often performed once per stay)
 - Common Inpatient Consulting Services
 1. Cardiology
 2. Endocrinology
 3. Neuropsychology for Neurocognitive Testing
 4. Otolaryngology

- 5. Occupational/Physical Therapy
- 6. Oncology
- 7. Pediatric Surgery
- 8. Speech Therapy
- Frequent Additional Autonomic Tests
 - 1. [Core and Peripheral Skin Temperature Testing](#)
 - 2. [Exogenous Ventilatory Gas Challenge](#)
 - 3. [Orthostatic Head-Up Tilt Challenge](#)
 - 4. [Pupillometry](#)
- Examples of Autonomic Testing in CAMP
 - [Heart Rate Deep Breathing \(HRDB\) Test](#)
 - [Orthostatic Head-Up Tilt \(HUT\) Test](#)
 - [Thermoregulatory Sweat Test \(TST\)](#)
 - [Q Sweat Test](#)
 - [Valsalva Maneuver Test](#)

[Back to Table of Contents](#)

What to Expect During Inpatient CAMP Admission (sample daily schedule)*

	Monday	Tuesday	Wednesday	Thursday	Friday
6:00 am		Return to 19 th floor	Return to 19 th floor	Return to 19 th floor	You and your healthcare team will complete a final review of the Autonomic Night Study, finalize discharge instructions, and review any questions.
6:30 am		Receive a chest X-ray			
7:00 am		Fasting bloodwork will be taken	Receive an Echocardiogram		
8:00 am	Admitted to the 19 th floor (Inpatient floor) on Autonomic Medicine service	A Cardiology Technician will place a Holter monitor on your child			
8:30 am		Return to Room #03-163 Daytime testing begins	Return to Room #03-163 Daytime testing begins	Return to Room #03-163 Daytime testing begins	
8:45 am			A Cardiology Technician will place a Holter monitor on you		Your CAMP summary documents will be prepared for your at-home physicians and medical care team. You will also receive a mailed copy of your child's medical records and summary documents.
9:00 am		Neurocognitive testing will take place	Exogenous Ventilatory Challenges will take place		
10:00 am				A neuropsychologist will meet with parents to review the neurocognitive testing results	
10:30 am	Room #03-163 (on the 3 rd floor) CAMP testing: Physiologic monitoring will be set up				
12:00 pm	A Cardiology Technician will place a Holter monitor on your child to receive an ECG				
2:00pm	Autonomic testing will take place starting with an Orthostatic Head-Up Tilt (HUT) Test	Autonomic testing will take place starting with a Thermoregulatory Sweat Test (TST)	Autonomic Testing will take place starting with Heart Rate Deep Breathing (HRDB). Followed by Valsalva Maneuver Test (VALS). And lastly, a QSWEAT test		You are ready to go home!
4:00pm	Daytime testing ends – return to room on the 19 th floor	Daytime testing ends – return to room on the 19 th floor	Daytime testing ends – return to room on the 19 th floor	Daytime testing ends – return to room on the 19 th floor	
9:30pm	Room #03-170 (CAMP Testing) Get ready for bed. Monitoring equipment will be placed on your child for a sleep study	Return to Room #03-170 Get comfortable and ready for bed	Return to Room #03-170 Get comfortable and ready for bed	Return to Room #03-170 Get comfortable and ready for bed	

*Schedules may vary as they are tailored to each patient

<i>Meal</i>	<i>Time* / Location</i> <i>*approximate</i>
Breakfast	Between 7:00-8:00am In your child's hospital room
Lunch	Between 11:00am-1:00pm In your child's hospital room
Dinner	Between 4:00-9:00pm In your child's hospital room

What does an overview of a 24-hour day at CAMP look like?

- Start the day at 6:00 a.m. in the CAMP Testing Night Room.
- A CAMP specialist will take off overnight monitoring equipment (leads/wires).
- The patient returns to the 19th floor, or the PICU on the 15th/16th floor, in pajamas.
- Once at the destination, the remainder of the monitoring equipment will be removed with assistance.
- Prep for the day: Order breakfast by using any hospital room phone and dialing #12345. You will be able to eat in your child's room. Shower and wash hair to remove residue from EEG head leads/wires (stickers with wires that go on your child's scalp).
- CAMP staff will pick you and your child up from the hospital room between 8:30 a.m. – 9:00 a.m. and bring you to the CAMP Testing Day Room on the 3rd floor.
- The daytime monitoring equipment will be applied to test physiologic changes during activities of daily living.
- At 4:00 p.m., the day testing concludes, some leads/wires will be removed, and the CAMP staff will escort you and your child back to their hospital room where the remainder of the leads/wires are removed.
- Between 4:00 p.m. – 9:00 p.m. your child has free time and can order dinner and get ready for bed.
- At 9:30 p.m., the CAMP team will escort your child from their room to the CAMP Testing Night Room and set up the monitoring equipment for the Autonomic Night Study.

COVID Testing

COVID testing will be done the weekend before your child's stay at a facility close to you.

If you have any questions, please call the Lurie Children's main hospital number (312-227-4000) and ask the operator to page the CAMP attending physician on call.

All visitors are required to wear a mask at all times while present in the hospital, primary care and outpatient centers.

***** Please check with your care team regarding current visitor guidelines *****

In addition:

- All visitors will have a health screen on entry and daily at their child's bedside.
- Anyone with symptoms of a viral illness such as fever, sore throat, cough, sneezing, runny nose, vomiting, or diarrhea will not be allowed to visit.
- Because people can spread these illnesses even before they show symptoms, anyone who has been exposed to a communicable disease in the past 30 days such as chicken pox, shingles, measles, tuberculosis (TB), mumps or whooping cough/pertussis will not be allowed to visit.
- Adult visitors (18 & older) will be required to show a valid government ID and will receive a hospital-issued badge with photo.
- No children or siblings under 18 are allowed to visit until further notice.
- There is no hospital entry between midnight and 6 am.
- Any patient suspected to have COVID-19 is isolated.
- Social distancing is practiced throughout all facilities.

What you should plan to bring to CAMP:

- Comfortable clothing and gym shoes
 - For infants and toddlers, bring onesies and clothing that doesn't cover their legs
- Primary and back-up ventilator
- All home monitors (including all pulse oximeters, end tidal capnography, and thermometers)
- Circuits on both ventilators, adapters, and the accessories used
- Equipment and tools that assist with developmental therapies
- Regularly used books, toys, games, and activities (for example, your child's favorite books or music playlists)
- School work for free time and quiet activity

Please call prior to your arrival to ensure CAMP has the appropriate adapters and accessories specific to your child's needs.

[Back to Table of Contents](#)

What follow-up to expect after a CAMP inpatient stay:

- A summary of the stay is compiled and communicated to your referring doctor.
- Within a week of discharge from CAMP, we will reach out with follow-up questions and updates.
- Your child often will be sent home with a prescription called a ventilator ladder. This is to adjust their ventilator settings as needed at home along with activity recommendations.

Questions you may want to ask your child's CAMP provider during the inpatient stay

If you are a parent who is coming to CAMP for the first time, or if your child has recently been diagnosed with an autonomic disorder, you might not know what to ask your child's provider at CAMP.

In order to better understand your child's condition, here is a list of questions you may want to ask your child's provider:

- How does carbon dioxide correlate with CCHS?
- What does carbon dioxide do to your body?
- Can you explain carbon dioxide and oxygenation?
- What does this condition (such as CCHS) affect?
 - What are the best outcomes?
 - What kind of support and care is needed for the best outcomes?
 - What are common misconceptions about CCHS that I should be aware of?
 - What is the difference between genotype and a phenotype?
 - What does the affected gene in this condition control?
 - What kind of gene abnormality do I have?
 - What kind of gene abnormalities exist for this condition and is there a difference in management and outcomes?
 - Why is CAMP important in managing this condition?
 - How do I care for this condition on a daily basis?
 - What types of emergencies can happen in this condition?
 - How do I care for this condition in emergencies?
 - What options exist to take care of the breathing abnormalities in this condition?

[Back to Table of Contents](#)

Common Inpatient CAMP Health Screening Tests and Assessments

- **Holter monitor:** This monitor is a series of leads and wires, or a small wearable device, that records the heart's rhythm. It's used to detect or determine the risk of irregular heartbeats. One Holter monitor study usually lasts for 24 hours.
- **Electrocardiogram (ECG):** This test is used to monitor heart rate and checks for any abnormal heart rhythms.
- **Echocardiogram:** This assesses the overall function and structure of the heart by ultrasound.
- **End tidal capnography:** The level of carbon dioxide that is released at the end of an exhaled breath is called “end tidal carbon dioxide” and it reflects the patient’s breathing status.
- **Near-infrared spectroscopy (NIRS):** This is a noninvasive technology (stays on the skin surface) that continuously monitors blood flow with a probe (which is a sticker and a wire).



- **Laboratory blood and urine tests:** Samples are taken to measure or examine cells, chemicals, proteins, or other substances in the blood. We do our best to limit the amount of blood testing.
- **Chest radiograph:** An X-ray is obtained to determine lung and airway structures.
- **Abdominal radiograph:** An X-ray is obtained to determine diaphragm and bowel patterns.
- **Abdominal ultrasound:** An ultrasound will assess large organs in the body.
- **Neurocognitive assessment:** Specialists will test the child’s cognitive processes and how it relates to their condition. Growth and development are key to optimizing outcomes and providing anticipatory guidance to support the child.

A picture of a complete daily set up of equipment under the shirt and outfit for the day.

[Back to Table of Contents](#)

Autonomic Testing

Pupillometry Test

This test measures the size of the pupil and its response to light. The results of this test help to measure differences in autonomic function and understand symptoms such as light sensitivity, dizziness, and headaches.

Special considerations before the test:

During the exam it is important to avoid blinking.

What are the risks?

A bright light may cause temporary vision discomfort.

What happens during the procedure?

1. Your child will be placed in a darkened room for about 1 minute prior to testing.
2. They will be instructed to look straight and not into the measuring device.
3. During the test, your child will be asked to keep their head straight and both eyes wide open.
4. With the room still dark, a handheld Pupillometer device (as shown in the picture to the right) will be held in front of their right eye. After a brief rest, the device will be held in front of their left eye.
5. They will be instructed to look straight. There will be a flash of light. Soon after, the test will be complete.



[Back to Table of Contents](#)

Orthostatic Head-Up Tilt (HUT) Test

Orthostatic “tilt table” testing is often used to determine a cause of symptoms such as dizziness, fainting, vision changes, or headaches. This test measures how changes in body position can affect blood pressure, heart rate, and cerebral perfusion (or the pressure system that maintains blood flow). The goal is to try to measure any physiological changes during the test and to see if any symptoms occur. This will help your referring doctor understand why the symptoms occur and consider options for management.

Special considerations before the procedure:

- Please send the medications your child is taking to CAMP and discuss changes in the medication schedule with your referring doctor ***before*** the HUT test. Be sure you contact the prescribing physician(s) before withholding or restarting any medication(s).
- Please be sure to let us know if your child starts any new medication prior to their upcoming appointment(s) since it could affect testing.
- Your child should not have any (non-prescribed) caffeine or chocolate in the 24 hours before testing.
- Drink 1 liter of water approximately 1-2 hours before testing.
- Maintain their regular meal and snack routine on the day of testing.

What are the risks?

The primary risk during this tilt is pre-fainting or fainting. For this reason, the test is closely supervised and your child will wear a strap to keep them safe and avoid falling off.

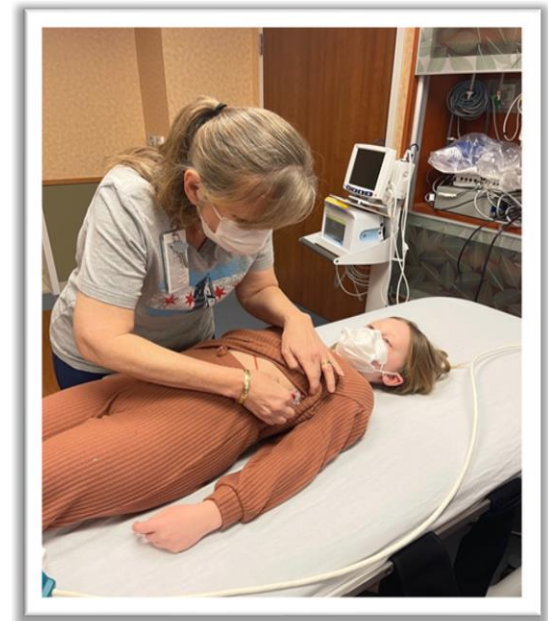
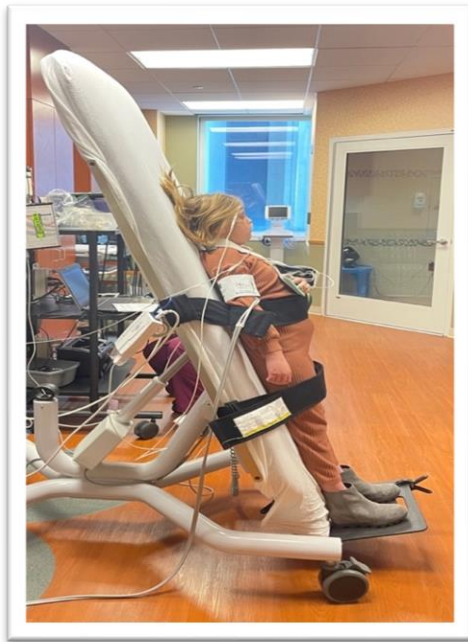
What happens during the procedure?

Your child will lie on a special table and straps will be placed across their waist and knees to help them safely stay in the correct position.



1. A CAMP provider will put a blood pressure cuff on one of their arms to monitor and check blood pressure throughout the test.

2. Then, electrodes (special stickers attached to wires) will be attached to their chest. These wires are attached to an ECG machine that lets the provider monitor their heart rhythm throughout the test.



3. The table will then be tilted so that your child is almost standing. They will stay in that position for 10 minutes. The provider will watch for changes in their blood pressure and heart rhythm. They will be observed for dizziness, fainting, and other symptoms. They will be asked to not talk during the test.
4. After 10 minutes, the table is returned to flat position and the test is finished. We will let them know once the test has ended and they can talk again.

A CAMP provider will ask your child to report any of the following symptoms during the test:

- A rapid heartbeat (palpitations)
- Dimmed vision
- Nausea
- Overall weakness
- Sweating or feeling lightheaded
- Other unusual symptoms

[Back to Table of Contents](#)

Heart Rate Deep Breathing (HRDB) Test

Deep breathing changes the amount of oxygen and carbon dioxide in the blood, which results in heart rate changes. The test is performed while your child is lying down and starts with a rest period that gives them time to relax. We usually record one minute before proceeding with the deep breathing test.

Special considerations before the procedure:

- Please send the medications your child is taking to CAMP and discuss changes in the medication schedule with your referring doctor **before** the HRDB test. Ensure to contact the prescribing physician(s) before withholding or restarting any medication(s).
- Please be sure to let us know if your child starts any new medication prior to their upcoming appointment(s) since it could affect testing.
- Your child should not have any (non-prescribed) caffeine or chocolate in the 24 hours before testing.
- Drink 1 liter of water approximately 1-2 hours before testing.
- Maintain their regular meal and snack routine on the day of testing.

What are the risks?

Symptoms such as dizziness or lightheadedness may take place during the test.

What happens during the procedure?

1. A CAMP provider will place a band around your child's chest.
2. A provider will direct them to take slow, deep breaths for 120 seconds. This will repeat 8 times.
3. The equipment will be removed and the test is complete.



[Back to Table of Contents](#)

Valsalva Maneuver Test

This test is a breathing technique that will require your child to breathe out forcefully through a mouthpiece while their nose is pinched shut.

Special considerations before the test:

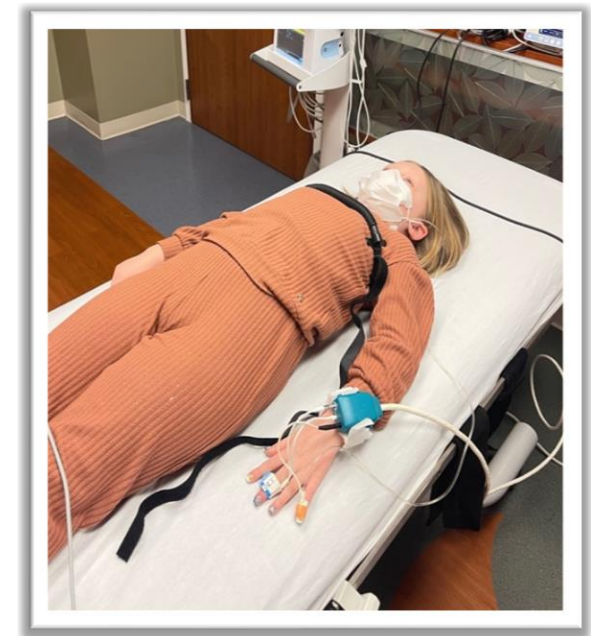
- Please send the medications your child is taking to CAMP and discuss changes in the medication schedule with your referring doctor before the test. Be sure to contact the prescribing physician(s) before withholding or restarting any medication(s).
- Please be sure to let us know if your child starts any new medication prior to their upcoming appointment(s) since it could affect testing.
- Your child should not have any (non-prescribed) caffeine or chocolate in the 24 hours before testing.
- Drink 1 liter of water approximately 1-2 hours before testing.
- Maintain their regular meal and snack routine on the day of testing.

What are the risks?

Symptoms of dizziness or lightheadedness may take place during the test.

What happens during the procedure?

1. A CAMP provider will place electrodes on your child's chest and a small blood pressure cuff on their finger.





2. A nose pincher will be placed on their nose and they will be handed a mouthpiece to blow in to.

3. Your child will then be asked to blow into the mouthpiece for 15 seconds. They can expect to follow the green light on a monitor to better assist the force of breathing. They will repeat the same step while inhaling deeply and following the monitor.

4. The equipment will be removed and the test is complete



[Back to Table of Contents](#)

Thermoregulatory Sweat Test (TST)

This test is used for diagnosing sweat abnormalities in children. It takes place in a special laboratory called a thermoregulatory chamber that has controlled temperature, humidity, and air flow regulation capabilities. This test can be useful for children who have difficulty tolerating heat or who sweat excessively.

Learn about our one-of-a-kind test chamber in this short documentary: <https://www.youtube.com/watch?v= QchbVXWIVQ>

Special considerations before the test:

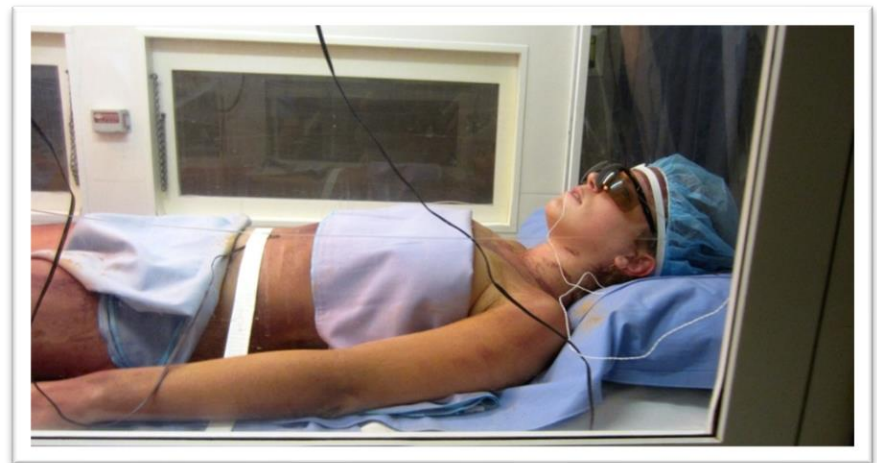
- The test can last up to one hour and it is important to remain still throughout the testing. Consider bringing favorite music or audio book to listen to during the test.
- The indicator powder used during the test is made from alizarin and takes about three washes to fully come off the skin.
- Shampoo and body wash will be provided. However, you are more than welcome to bring your own.
- Coconut oil can also help in the removal of the powder.

What are the risks?

The primary risk for this test is symptoms of feeling overheated or light-headed.

What happens during the procedure?

1. A CAMP provider will ask your child to change into disposable paper swimming trunks (and tube top for those who would like to cover their chest) as well as a paper head cover, eye goggles, and a face mask.



2. Your child will then lie on their back on a gurney bed outside of the thermoregulatory chamber. A provider will sprinkle an alizarin-based indicator powder on their skin that will help to see if they are sweating or not. This powder will be yellow/brown at first, but changes to dark purple as your child sweats.



During the TST, the yellow/brown indicator powder will turn purple with sweating.

3. Your child will then be rolled into the preheated thermoregulatory chamber. Both ambient heat and humidity are controlled in the chamber by using infrared heat lamps to cause them to sweat. The heat lamps are used to increase core body temperature by at least 1 degree Celsius. Temperature checks will occur until the goal temperature is reached.





4. At completion of test, CAMP staff will move your child outside the chamber and help them remove their goggles, hat, and monitors. They will be given iced water to drink and a handheld fan to return to a more comfortable temperature. After their body has cooled down, they then can shower to begin removing the indicator powder.

[Back to Table of Contents](#)

Quantitative sudomotor axon reflex test (Q Sweat Test)

This test measures the nerve response that controls sweating. It involves slight electric stimulation on the skin to stimulate sweat glands. The test measures the volume of sweat produced by this stimulation.

Special considerations before the test:

1. Please send the medications your child is taking to CAMP and discuss changes in the medication schedule with your referring doctor before the test. Ensure to contact the prescribing physician(s) before withholding or restarting any medication(s).
2. Please be sure to let us know if your child starts any new medication prior to their upcoming appointment(s) since it could affect testing.
3. Your child should not have any (non-prescribed) caffeine or chocolate in the 24 hours before testing.
4. Drink 1 liter of water approximately 1-2 hours before testing.
5. Maintain their regular meal and snack routine the day of testing.

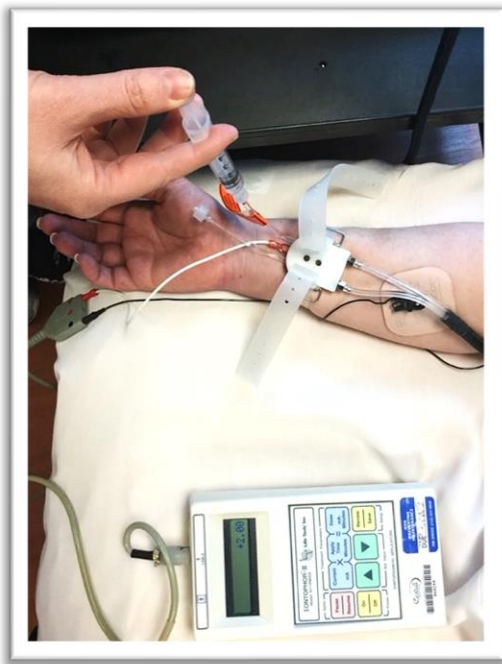
What are the risks?

A mild stinging discomfort and redness may be experienced at the site of stimulation during the test.

What happens during the procedure?

1. The CAMP provider will wipe the skin on your child's foot, leg, and wrist with alcohol to clean the area.





2. A wrist-watch like device with a chamber is filled with a liquid medication called acetylcholine to cause sweating in the area where the device is placed. It will be placed on three areas of their leg and one on the wrist. No needles are involved

3. The stimulators will be turned on and the slight electrical stimulation is used to stimulate the skin to sweat. Your child's sweat responses will then be measured by the specialist.



[Back to Table of Contents](#)

Common Inpatient Testing: Autonomic Tests

Orthostatic Head-Up Tilt (HUT) Test

Orthostatic “tilt table” testing is often used to determine a cause of symptoms such as dizziness, fainting, vision changes, or headaches. This test measures how changes in body position can affect blood pressure, heart rate, and cerebral perfusion (or the pressure system that maintains blood flow). The goal is to try to measure any physiological changes during the test and to see if any symptoms occur. This will help your referring doctor understand why the symptoms occur and consider options for management.

Special considerations before the procedure:

- Please send the medications your child is taking to CAMP and discuss changes in the medication schedule with your referring doctor **before** the HUT test. Be sure you contact the prescribing physician(s) before withholding or restarting any medication(s).
- Please be sure to let us know if your child starts any new medication prior to their upcoming appointment(s) since it could affect testing.
- Your child should not have any (non-prescribed) caffeine or chocolate in the 24 hours before testing.
- Drink 1 liter of water approximately 1-2 hours before testing.
- Maintain their regular meal and snack routine on the day of testing.

What are the risks?

The primary risk during this tilt is pre-fainting or fainting. For this reason, the test is closely supervised and your child will wear a strap to keep them safe and avoid falling off.

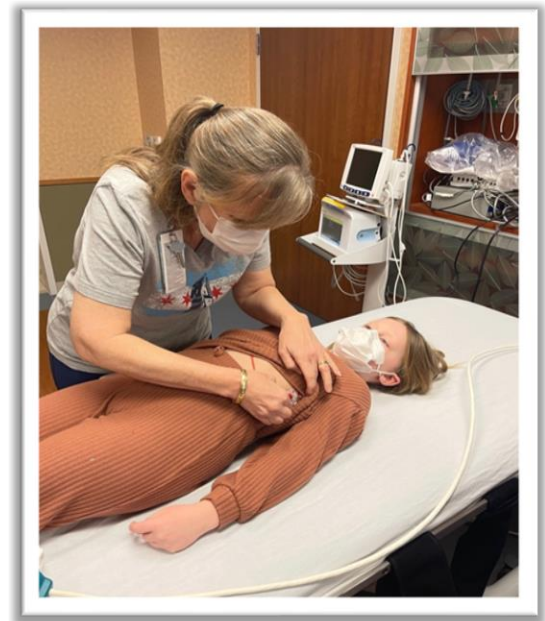
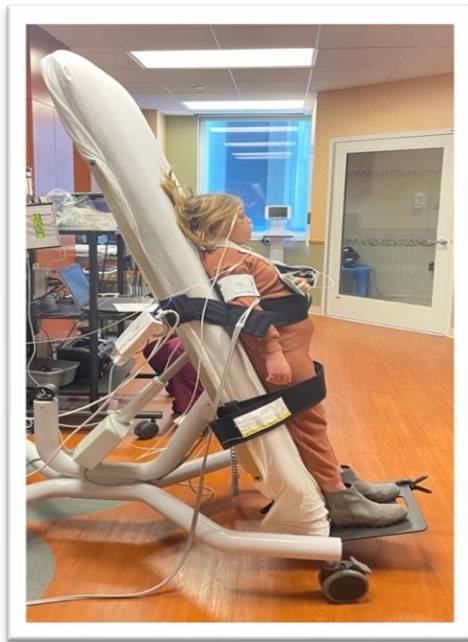
What happens during the procedure?

Your child will lie on a special table and straps will be placed across their waist and knees to help them safely stay in the correct position.



5. A CAMP provider will put a blood pressure cuff on one of their arms to monitor and check blood pressure throughout the test.

6. Then, electrodes (special stickers attached to wires) will be attached to their chest. These wires are attached to an ECG machine that lets the provider monitor their heart rhythm throughout the test.



7. The table will then be tilted so that your child is almost standing. They will stay in that position for 10 minutes. The provider will watch for changes in their blood pressure and heart rhythm. They will be observed for dizziness, fainting, and other symptoms. They will be asked to not talk during the test.
8. After 10 minutes, the table is returned to flat position and the test is finished. We will let them know once the test has ended and they can talk again.

A CAMP provider will ask your child to report any of the following symptoms during the test:

- A rapid heartbeat (palpitations)
- Dimmed vision
- Nausea
- Overall weakness
- Sweating or feeling lightheaded
- Other unusual symptoms

[Back to Table of Contents](#)

Pupillometry Test

This test measures the size of the pupil and its response to light. The results of this test help to measure differences in autonomic function and understand symptoms such as light sensitivity, dizziness, and headaches.

Special considerations before the test:

During the exam it is important to avoid blinking.

What are the risks?

A bright light may cause temporary vision discomfort.

What happens during the procedure?

1. Your child will be placed in a darkened room for about 1 minute prior to testing.
2. They will be instructed to look straight and not into the measuring device.
3. During the test, your child will be asked to keep their head straight and both eyes wide open.
4. With the room still dark, a handheld Pupillometer device (as shown in the picture to the right) will be held in front of their right eye. After a brief rest, the device will be held in front of their left eye.
5. They will be instructed to look straight. There will be a flash of light. Soon after, the test will be complete.



[Back to Table of Contents](#)

Peripheral Skin Temperature Testing

This test is used for autonomic temperature regulation in the distal extremities (hands and feet).

Special considerations before the test:

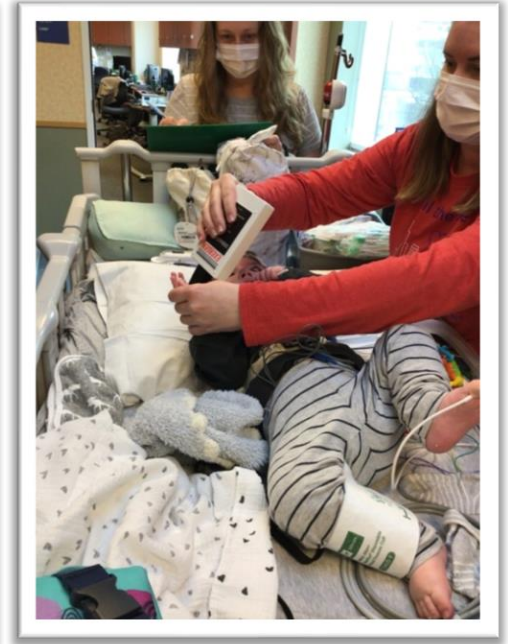
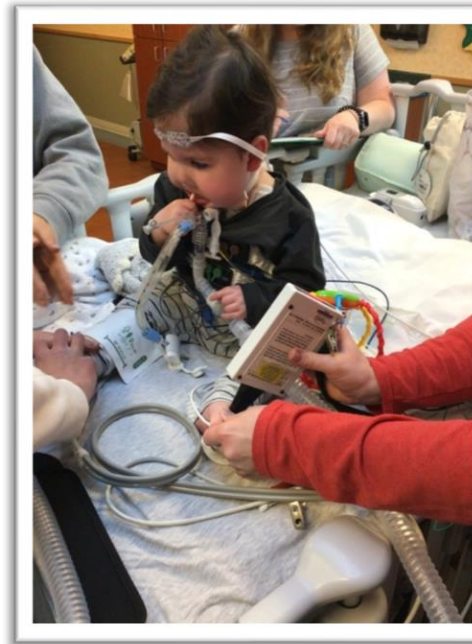
None

What are the risks?

None

What happens during the procedure?

1. A hand-held device will be used to measure skin temperature
2. A CAMP specialist will measure skin temperature on each hand and foot in 5 specific locations.



Exogenous Ventilatory Gas Challenges

This test is completed to see how the whole body responds to various levels of carbon dioxide and oxygen.

[Back to Table of Contents](#)

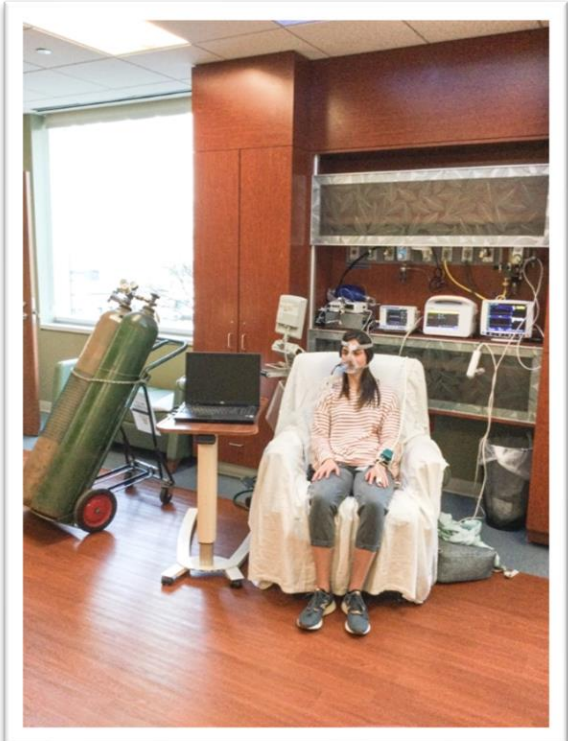
Special considerations before the test:

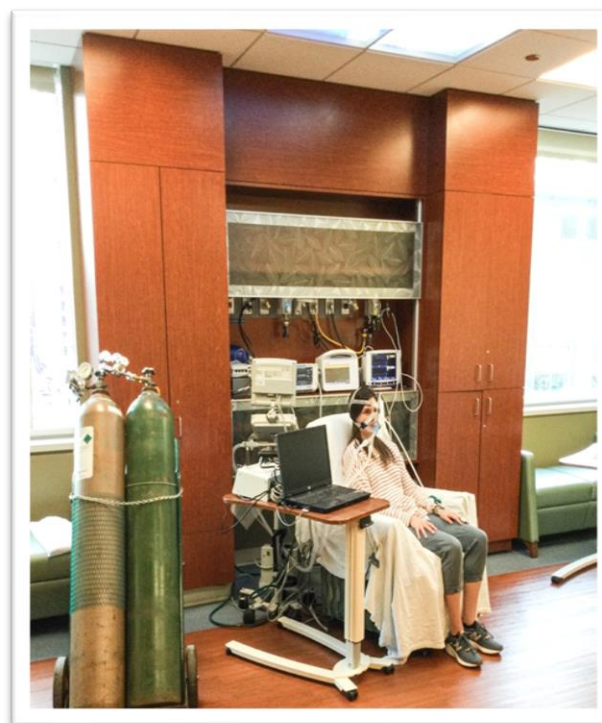
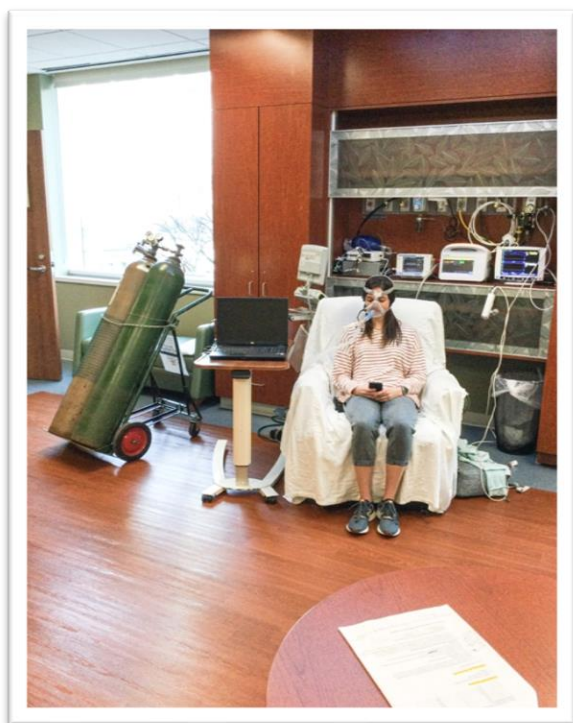
The test requires quiet and stillness while seated for up to an hour. Consider bringing a phone or iPad to watch a movie or listen to music or a book during this time.

What are the risks?

Symptoms can occur after breathing in the gas mixture including feelings of shortness of breath or a minor headache.

What happens during the procedure?

1. Your child will be seated in a comfortable chair to rest quietly. A large face mask will be placed on their face with tubing attached to a ventilator.
- 
- The photograph shows a young child sitting in a white medical chair in a clinical setting. The child is wearing a large, clear face mask connected to a ventilator system. To the left of the chair is a tall green oxygen tank on a cart. In the background, there are medical monitors and equipment on a stand. The room has wood paneling and a large window.
2. They will breathe a carefully controlled mixture of oxygen and carbon dioxide, while their respiratory rate, heart rate, oxygen saturation, end-tidal carbon dioxide, and more are measured. They can be on an iPad or watch a movie during this time.



[Back to Table of Contents](#)

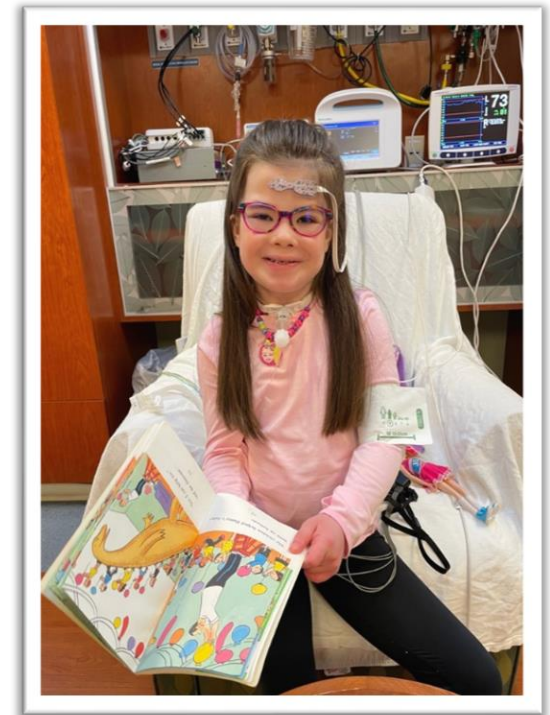
Inpatient Autonomic Day Study

Broadly, CAMP specialists try their best to mimic your child's daily life (i.e., doing schoolwork and reading, walking, various levels of exertion, playing with siblings etc.) and their school/home environments to see how they breathe and their body responds during these daily tasks.

Day time studies typically start around 8:30 a.m. and end at 4:00 p.m. A CAMP specialist will pick your child up from their hospital room and bring them to CAMP room on the third floor. They are seated on a comfortable chair while a specialist attaches equipment including:

- Chest and abdominal bands
- Chest stickers for leads
- Near-infrared spectroscopy (NIRS) probe on forehead
- Capnography (to measure exhaled carbon dioxide) via nasal canula on face or tracheostomy tube
- Blood pressure cuff on arm
- Pulse oximeter (to measure oxygen saturation, or level of oxygen in the blood) on their hand or foot.

Your child will be allowed to watch TV or play on their iPad during set up.



[Back to Table of Contents](#)

Inpatient Autonomic Night Study

Night sleep studies typically start at 9:00 p.m. and end at 6:00 a.m. Your child will use the bathroom, brush their teeth and change into their pajamas brought from home in their hospital room. A CAMP specialist will pick your child up from their hospital room and bring them to the CAMP Night Study room on the 3rd floor of Lurie Children's. Younger patients are wheeled down in their crib/bed.

Your child is allowed to watch movies, be on their phones, and chat while a specialist sets up the equipment. The equipment used during overnight testing includes:

- A blood pressure cuff or a finger blood pressure monitor for older kids
- Lead stickers and wires
- Chest and abdominal bands
- EEG head leads
- Capnography (to measure exhaled carbon dioxide) through a nasal canula or tracheostomy tube
- Near-infrared spectroscopy (NIRS) with a forehead probe.

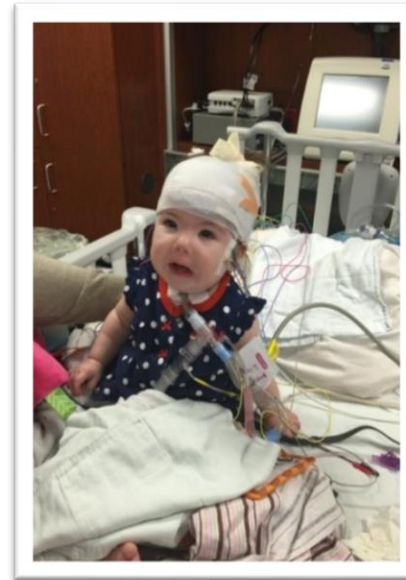
Your child's head will get wrapped in gauze so the electrodes on their head stay in place for the night.

CAMP specialists try their best to mimic your child's home bedtime and bedtime routine. Older children are allowed to stay up and watch movies or sleep at their own time. Throughout the night a specialist will check home monitors and ventilator settings. They often perform a step-wise sleep test while falling asleep (sleep-onset trial) and during sleep (intra-sleep trial) to examine breathing. The team will watch your child and the information from the equipment that they're wearing over night to see how they respond to various stages of sleep and during the tests. The equipment is monitoring:

- EKG
- EEG
- Blood pressure
- Inductance plethysmography bands (breathing)
- End tidal (exhaled) carbon dioxide levels
- Oxygen saturation
- And more



This information gathered by this equipment is being reviewed by the specialists in real-time and summarized after the night's sleep. At 6:00 a.m. your child will have the monitors stopped, some leads removed, and often receive an additional image such as echocardiogram, chest radiograph, or abdominal ultrasound in Lurie imaging or the hospital room. Most of the other studies are completed by 7:00 a.m. to allow for daytime preparation in the hospital room, including showering and eating breakfast.



[Back to Table of Contents](#)

We are looking forward to caring for your child!

Please reach out to your care team with any questions or concerns you may have!



All,
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one.®



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