

Travel Guide: Bethesda MD (NIH)

One of the places you may end up taking your child for NB treatment is the National Institutes of Health, or NIH. This is the U.S. government's National Cancer Institute, and it is located in Bethesda, Maryland, right outside of Washington, DC.

If you fly into Washington, DC, the NIH offers shuttle buses free of charge from the major airports. There is a schedule on the NIH website. You can also drive to the NIH. Since 9/11, there is very tight security. Your vehicle and your belongings will be inspected upon entry onto the campus. You will also be given a security badge that is just temporary. Ask the staff at the clinical center about arranging for a permanent security badge. It will last a year, and it will make coming and going from the campus very easy. You will also need a security badge to enter the campus from the Metro. There is a Metro station right on the campus, and it makes it a breeze to go enjoy Washington, DC and all it has to offer.

Once a patient at the NIH, your expenses are paid for, as well as the treatment. Travel is covered, as well as meals, scans, tests, and the drugs administered. Literally the only expense you will have is the cost of travel to get to the NIH for the first visit.

You will most likely stay at The Children's Inn at NIH. It is a wonderful facility, renovated just a few years ago. The accommodations are very comfortable and the staff there is used to dealing with all kinds of patients and their families. You will stay in a hotel room that includes a television with cable, a full bathroom, and two double beds. Linens are provided free of charge, but you are expected to keep your room clean and to clean it when you leave. There is maid service but not daily. There are washers and dryers provided, as well as laundry detergent. Whether you stay one day or two months, The Children's Inn staff will try to make your stay as comfortable as possible.

One restriction enforced is that you cannot eat in your room. That is fine, because there are several very large kitchens with eating areas. You are assigned a refrigerator that you share with two or three other families, as well as a pantry. The Inn provides a lot of basics, like condiments, dishes, pots and pans. There are also daily grocery store runs to stock up on what you need. There are even grills outside to use when the weather is nice. You can also order out from a large variety of restaurants in Bethesda and the surrounding area that will deliver. The main desk keeps a folder of menus.

The Children's Inn provides specific refrigerators for medicine that needs to be kept cold or things like a 24-hour urine collection. There is a bank of computers specifically for children, and a business office for adults. The Children's Inn also has an exercise room. There are flat screen televisions throughout the Inn with the schedule of activities, the airport shuttle schedule, the local date and time, and a running ticker of the latest news. A constant shuttle service is provided from the Inn to the clinical center for treatment, which is good since the walk to the clinical center is straight uphill!

Another benefit of the Inn is free long distance calls, so having no cell phone is no problem. The room phones can be used only for local calls, but free long distance calling is available on the many telephones in the hallways at the Inn. The NIH staff likes for you to sign in and out of the Inn, just so they know where you are, and how to get in touch with you should they need to discuss any changes in treatment or other items.

The NIH has a cafeteria that, while small, is still quite good, and has a small coffee shop that stocks

snacks and other items you may need. It also has a library and a chapel.

The NIH has an active child life organization, and The Children's Inn provides several activities for children and parents to enjoy. For example, there are trips to the local zoo and sporting events, and dinners at local hotels. There is bingo (with great prizes), and arts and crafts activities. There are large screen televisions, air hockey and video games, and an outdoor play area. Each child is assigned a mailbox - not for regular mail, but for regular gifts! Each day your child will receive a special little gift - or maybe several.

The NIH voucher office is where you will be reimbursed for travel and meals. This will need to be coordinated with your clinic. When the first appointment is made for your child, you will be discussing these matters with the patient coordinator. Also, the coordinator will make the first reservation at the Children's Inn. After that point, you will make all the follow up reservations at the Children's Inn yourself, either at your discharge from the first visit, or on-line or by phone.

Many families from all over come to the NIH and stay at The Children's Inn. Right beside the main desk is a map of the world; take the pin related to your room, and put it on your hometown. It is amazing to see how far some children come for treatment. There always seems to be someone to talk to or play with at the Inn and at the clinical center. Other parents reach out to each other, and children make lifetime bonds within moments, let alone days.

These two websites have all the information you will need about the NIH:

www.childrensinn.org and www.nih.gov

Please contact info@cncfhope.org with any comments