

Travel Guide: Burlington, Vermont (UV)

One of the options for treatment of either refractory or relapsed neuroblastoma is at Fletcher Allen Health Care/Vermont Cancer Center in Burlington, Vermont. Dr. Giselle Sholler and her team have developed a clinical trial utilizing nifurtimox along with two chemotherapy agents (topotecan and cyclophosphamide) as well as Zometa to treat our children. Other preclinical studies are ongoing.

THE HOSPITAL

Fletcher Allen Health Care is located in Burlington, Vermont on the campus of the University of Vermont. Several neuroblastoma families are seeking treatment there, primarily those who have already tried other options for refractory or relapsed NB. It is a small center for such a busy oncology practice, but Dr. Sholler and her team do everything practicable to make it easier for the families.

For example, there is no pediatric oncology unit - neither a specialized clinic or inpatient unit. Pediatric oncology outpatient treatment is at the Children's Specialty Clinic - where other specialties are housed as well. The infusion bay is for the entire Specialty Clinic. There are three very small bays where chemo and transfusions are handled. Bone marrow aspirates and biopsies are done in the Specialty Clinic as well - not in outpatient surgery. If you do go there, ignore the people in Admissions - it does not matter how many times you tell them, they still insist you go to outpatient surgery for a bone marrow procedure.

The hospital itself is a maze of different buildings built at different times. The Children's Specialty Clinic is in the main hospital, as is Admissions and Registration. Scans and the inpatient unit are done in an older part of the hospital. It can be confusing, but everyone is very helpful, and once you get to the main hospital entrance, someone will point you in the right direction. We always found a wheelchair if we needed it, and there is plenty of underground parking at the hospital. The clinic will stamp your ticket so that you do not have to pay for parking. Additionally, if you have a handicapped placard from your home state, parking is free.

Vermont does not issue handicapped placards to non-residents; however, the state does honor any other state's handicapped placard. If your child needs handicapped parking, then do this before you come to Vermont and bring the placard with you. Even if your child is ambulatory when you leave your home state, this might be a good idea, since the nifurtimox trial can cause pain and problems with walking.

The food in the hospital is relatively good. Vermont is known for lots of food products, including Ben & Jerry's ice cream, Cabot cheese, and of course, maple syrup. Vermont locals are also proud of being "green" and eating lots of organic foods.

There are a lot of child life therapists at Fletcher Allen, and they are very good at entertaining the children.

WHERE TO STAY

There are many hotels in the area, and the hospital is only about ten minutes away from the airport.

The Ronald McDonald House in Burlington is on South Winooski Avenue. The hospital is just about a mile up the road - but it is a long mile and straight uphill. The RMH does have a shuttle van, and the social worker (Penny DeGoosh at the time this was written) can help with cab fare vouchers if necessary.

The RMH is an old Victorian house that has been renovated, and was given to the RMH organization by the church that sits next door. Some rooms do not have televisions, and even though there is WiFi access for computers, it can be spotty. The rooms are comfortable, and can fit four nicely. A few of the rooms are actually suites, with a bedroom, living room, and bathroom. The kitchen is fully stocked and every day someone brings dinner. The RMH also provides staples like eggs, milk, butter, and juice, and has some donated items like cereal, soup, and spaghetti sauce and noodles. There are two large refrigerators, but they are usually packed to the hilt with leftovers and guests' personal items. There is very little dry storage for guests. There is a playroom and a large yard with a playground. The director, Pam, and house manager, Amy, are very accommodating and can arrange for anything you need. During a recent visit, they were acquiring small refrigerators in each guest room for medications that must be refrigerated.

The best part of the RMH is its location. It is one block away from Church Street - a five-block section of downtown Burlington that is closed to vehicle traffic, and has tons of restaurants and shops. It is a very pleasant place to spend time for everyone in the family. It is also only a few blocks away from the waterfront. Burlington sits on the shores of Lake Champlain. There is a beach close by, and the waterfront has a walking/running/biking path.

The RMH has also arranged for guests to have temporary passes to the YMCA and the local library. Some people stay at the RMH for an extended time, and some families have even enrolled their children in the local schools. There is an elementary and middle school four blocks away from the RMH.

ACTIVITIES

Vermont is very small, and filled with things to do to keep your family active. It is also relatively easy to find your way around. Some examples:

- Ben & Jerry's ice cream factory - tours, samples and museum
- Cabot cheese factory - tours, samples and museum
- Vermont Teddy Bear factory - tours
- Pizza Putt - kind of like a big Chuck E Cheese
- Fairbanks Museum - lots of stuffed (real) animals, Vermont history
- Skiing - Vermont has so many ski resorts, too many to mention!
- ECHO - an aquarium and Lake Champlain museum

TRAVEL

Burlington has an international airport, although it is very small. There is only one waiting room for outgoing flights. There are a lot of rental car places in the airport. It takes ten minutes to get to the hospital and the RMH from the airport. Turbulence can be expected when you fly in because of the mountains that surround Burlington.

WEATHER

Expect eight months of winter - and tons of snow. Still, everyone there knows how to deal with it. The roads are usually plowed promptly and everything continues on as normal during a big snowstorm. The summer months usually have ideal weather with comfortable highs and lows. If you are going in the winter, take snow boots and layer everything. Sometimes the highs don't get above

the teens. Each business and the hospital overcompensate, and heat inside buildings is usually very warm.

Websites for more information

Details about the clinical trial:

<http://www.cancer.gov/search/ViewClinicalTrials.aspx?cdrid=558526&version=HealthProfessional&protocolsearchid=4711221>

Story and slide show about Dr. Sholler with some patients:

www.burlingtonfreepress.com/legacy/slideshows/040808neuroblastoma/index.html

Ronald McDonald House Vermont:

www.rmh-vermont.org

Ben & Jerry's Factory Tour:

www.benjerry.com/scoop_shops/factory_tour/

Cabot Cheese Factory Tour:

www.cabotcheese.com/fl.php?left=menu-visit.html&right=visit.html

Vermont Teddy Bear Factory Tour:

www.shop.vermontteddybear.com/tour-essentials.html

Fairbanks Museum:

www.fairbanksmuseum.org

ECHO Museum:

www.echovermont.org

Pizza Putt:

www.pizzaputt.com

Please contact info@cncfhope.org with any comments