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# Living Without Regrets: Tips for Traveling the World with Optune®

By Sandy, Optune caregiver, and Ira, Optune patient • 6 min read

Despite the inherent uncertainty tied to a glioblastoma diagnosis, we maintain a positive outlook which includes the emphasis on living our lives without any regrets. If we wanted to resume our busy travel schedule, Ira needed to remain active throughout his standard of care treatments. Since he did not experience any significant side effects from the craniotomy, the radiation, or the chemotherapy, it was possible for us to walk every day and exercise together several times a week in our basement. Being physically fit is a prerequisite for participating in active adventures, and Ira engaged in these activities with his doctor's permission. Ira was determined that his glioblastoma treatments would not prevent him from downhill skiing, riding a horse, snorkeling in the ocean, hiking at elevation, or touring for hours at historical sites.



#### **Creating a bucket list for travel**

To maintain our forward-looking mindset, we focused on planning future vacations. To help narrow down our choices, Ira created a bucket list. COVID

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possible, we prefer to travel independently or in smaller groups rather than being part of a large group. Cruise ship itineraries allow us to explore an assortment of destinations without the need to pack and unpack, drive long distances, or be concerned about where we are going to eat.



#### **Preparing for adventures**

Shortly after making our reservations, I investigated our travel insurance options. Travel insurance for individual trips that include preexisting conditions usually needs to be booked within a certain time frame and the insured parties need to be well enough to travel on the date the policy is issued. It is also possible to purchase annual policies for trip-related issues as well as for medical concerns.

Two weeks before traveling, we take an inventory of our Optune supplies and order whatever we need. Before packing our suitcases, we pull the required number of items, along with a few extras. It is advisable to double-check everything so that you won't be shortchanged upon arrival. Whatever doesn't fit into the Pelican case provided by Novocure is placed in our other carry-on luggage. We don't want to risk the possibility of a shortage of arrays if our checked baggage is accidentally lost in transit. While we have yet to contact nCompass<sup>®</sup> while we are traveling, we know that we can receive support from a representative if necessary.

Keep in mind that medical equipment is exempt from the rules for carry-on luggage. However, it can be cumbersome if you, like us, need to bring along two CPAP machines, computers, camera equipment, medicine, and the Optune supplies. While you may not take all these items, you may be surprised by the total volume and weight of the gear. Make sure you can manage.



### Finding humor in public reaction

Anyone who uses Optune or walks next to an Optune user knows that the headgear and battery pack may cause people to stare. Sometimes it could be a simple glance while other times people become fixated. To cope with the abundance of unwanted attention, we joke about these encounters. We would be very wealthy if we could sell tickets for the extra time that strangers spend staring at Ira's Optune.



#### Our elevator pitch for curious bystanders

Curiosity and boldness cause random individuals to approach us. This has occurred in the U.S. and when we are traveling in other countries. In Boulder, Colorado, we were greeted by a woman whose husband had worn the device. It was the first time she had seen anyone using Optune other than her husband.

Usually, people simply want to know why Ira is wearing the device and what it does. Our elevator pitch is short and sweet. We simply state that the device and arrays on Ira's head are designed to help prevent the tumor from returning. Most are content with this simple explanation. However, we have engaged in prolonged conversations with people who ask a series of detailed questions. This usually happens when the person either knew someone who passed away from glioblastoma or has a friend or relative currently coping with the disease. We are happy to educate others about glioblastoma and Optune.



#### The joys of traveling with Optune

Our airport experiences are never the same. Sometimes, Ira goes through security checkpoints without any issues while other times those checkpoints are not as smooth. One time, Ira was escorted to an area that I could not see. After 20 minutes, I asked a TSA agent to find him so that we would not miss our flight. Apparently, Ira was waiting for a TSA agent to pat him down. Familiarity with Optune obviously speeds up the process. Since the time needed to go through security is unpredictable, we recommend arriving quite early and asking for a TSA supervisor. Another option is to fill out the form on the TSA Cares website so the TSA staff is given a heads-up before you arrive at the security area.

Before a scheduled cruise, we let the cruise ship company know that we are traveling with Optune. With advance notice, the cruise ship's security team knows what to expect when we arrive at the port. Fortunately, we have yet to experience any issues with the security personnel at international ports of call.

On two separate international flights, Ira was asked by a flight attendant to provide proof that he was well enough to travel. Even though we didn't have a doctor's note, we were able to describe the purpose of the device and why Ira was healthy enough to travel. As a result, Ira's neuro-oncologist has provided a letter in the event it is needed for future international travels.

Be prepared for the lack of electrical outlets in international hotels and aboard cruise ships. With a limited number of outlets, it may not be possible to simultaneously plug in cell phones, computers/tablets, CPAP machines, the Optune battery charger, and the electrical unit for sleeping.



#### **Traveling with a companion**

By traveling together as a couple, we can share the responsibility of carrying everything that we need while making long travel days more tolerable by being together. Humorous comments are interjected throughout our days. While walking through the airport, I often detect the device's beeping sound before Ira hears it. If his hands are full, I can reset the device and look for loose connections. Our shared travel adventures add to our ability to live without regrets.

#### **Topics: <u>Daily Life with Optune, For Caregivers, Support Resources</u>**



By Sandy, Optune caregiver, and Ira, Optune patient

## **Recommended for you**



Alleviating Annoyances with Optune,<sup>®</sup> An Honest Review

By JB, Optune Patient



Faith and Hope with GBM

By Lynn, Optune® patient



**Optune® and Travel Security** 

#### By Pat, Optune Caregiver

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#### What is Optune® approved to treat?

Optune is a wearable, portable, FDA-approved device indicated to treat a type of brain cancer called glioblastoma multiforme (GBM) in adult patients 22 years of age or older.

#### Newly diagnosed GBM

If you have newly diagnosed GBM, Optune is used together with a chemotherapy called temozolomide (TMZ) if:

- Your cancer is confirmed by your healthcare professional AND
- You have had surgery to remove as much of the tumor as possible

#### Recurrent GBM

If your tumor has come back, Optune can be used alone as an alternative to standard medical therapy if:

- You have tried surgery and radiation and they did not work or are no longer working AND
- You have tried chemotherapy and your GBM has been confirmed by your healthcare professional

#### What is Optune Lua<sup>™</sup> approved to treat?

Optune Lua is a wearable, portable, FDA-approved device indicated for the treatment of adult patients, with unresectable, locally advanced or metastatic, malignant pleural mesothelioma (MPM) to be used together with standard chemotherapy (pemetrexed and platinum-based chemotherapy).

#### Who should not use Optune for GBM or Optune Lua for MPM?

Optune for GBM and Optune Lua for MPM are not for everyone. Talk to your doctor if you have:

- GBM and an implanted medical device (programmable shunt), skull defect (missing bone with no replacement) or bullet fragment. Optune has not been tested in people with implanted electronic devices, which may cause the devices not to work properly, and Optune has not been tested in people with skull defects or bullet fragments, which may cause Optune not to work properly
- MPM and an implanted electronic medical device including a pacemaker, implantable automatic defibrillator, etc. Optune Lua has not been tested in people with implanted electronic devices, which may cause the devices not to work properly
- A known sensitivity to conductive hydrogels (the gel on the arrays placed on the scalp or upper body like the ones used on EKGs). When Optune/Optune Lua comes into contact with the skin, it may cause more redness and itching or may rarely cause a life-threatening allergic reaction

## **Do not use Optune for GBM or Optune Lua for MPM if you are pregnant or are planning to become pregnant.** It is not known if Optune/Optune Lua is safe or effective during pregnancy.

#### What should I know before using Optune for GBM or Optune Lua for MPM?

Optune and Optune Lua should only be used after receiving training from qualified personnel, such as your doctor, a nurse, or other medical staff who have completed a training course given by Novocure<sup>®</sup>, the maker of Optune and Optune Lua.

- Do not use any parts that did not come with the Optune Treatment Kit or Optune Lua sent to you by Novocure or given to you by your doctor
- Do not get the device or transducer arrays wet
- Please be aware that Optune and Optune Lua have a cord that may cause tripping when connected to an electric socket
- If you have an underlying serious skin condition where the transducer arrays are placed, discuss with your doctor whether this may prevent or temporarily interfere with Optune or Optune Lua treatment

#### What are the possible side effects of Optune for GBM and Optune Lua for MPM?

The most common side effects of Optune when used together with chemotherapy for GBM (temozolomide or TMZ) were low blood platelet count, nausea, constipation, vomiting, tiredness, seizure, and depression.

The most common side effects when using Optune alone for GBM were scalp irritation (redness and itchiness) and headache. Other side effects were malaise, muscle twitching, fall and skin ulcers.

The most common side effects of Optune Lua when used together with chemotherapy for MPM (pemetrexed and platinum-based chemotherapy) were low red blood cell count, constipation, nausea, tiredness, chest pain, fatigue, skin irritation from device use, itchy skin, and cough.

Other potential adverse effects associated with the use of Optune Lua include: treatment related skin irritation, allergic reaction to the plaster or to the gel, electrode overheating leading to pain and/or local skin burns, infections at sites of electrode contact with the skin, local warmth and tingling sensation beneath the electrodes, muscle twitching, medical device site reaction and skin breakdown/skin ulcer.

Talk to your doctor if you have any of these side effects or questions.

Caution: Federal law restricts Optune Lua to sale by or on the order of a physician. Humanitarian Device. Authorized by Federal Law for use in the treatment of adult patients with unresectable, locally advanced or metastatic, malignant pleural mesothelioma concurrently with pemetrexed and platinum-based chemotherapy. The effectiveness of this device for this use has not been demonstrated.

Please <u>click here</u> to see the Optune Instructions for Use (IFU) for complete information regarding the device's indications, contraindications, warnings, and precautions.

# Please <u>click here</u> to see the Optune Lua IFU for complete information regarding the device's indications, contraindications, warnings, and precautions.

On this site, patient and healthcare professional videos as well as all images labeled as Optune users, caregivers, or healthcare professionals depict actual patients, caregivers, and healthcare professionals. All other depictions of patients and caregivers are actor portrayals. Patient images reflect the health status of the patients at the time each photo was taken.

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