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General Instructions and Emergency Procedures for Intrathecal Baclofen Pump

We at the Center for Cerebral Palsy at UCLA want to make sure that you, your family and those who care for you are fully informed about your baclofen pump and the procedures to follow in the unlikely event of an emergency. First, we recommend that you have the following with you at all times:

1. *Your Medtronic Emergency Medical Information card* – This has the signs and symptoms of overdose, underdose and withdrawal that are explained in this sheet, along with the number for Medtronic Technical Support. If you do not have card, or if Dr. Oppenheim is not listed as your physician, please contact Medtronic at (800) 707-0933.
2. *The most recent copy of your interrogation report* – This indicates your dosage and alarm date. We make every effort to give you a return visit appointment at the end of every refill. If for some reason you were unable to make a follow-up appointment for your refill, please note your alarm date and call us at your earliest convenience to schedule your next visit.
3. *A Medic Alert bracelet* – This is important in the event that you are in a medical emergency and are unable to tell the people caring for you that you have an ITB pump. Applications for a Medic Alert are available in the CP clinic, or online at the www.medicalert.org.

Pump Alarm

Your pump has two internal alarms that will go off when pre-set events occur. The best way to avoid hearing the alarm is to see the physician and have your pump refilled at the designated time before your alarm date.

The ***non-critical alarm*** is a single tone, or beep, that sounds like a faint digital wristwatch alarm. It will sound under three conditions:

1. On the alarm date – This is when the amount of drug left in the pump (the reservoir volume) gets to a pre-determined amount. This is usually set at 2 cc. Typically you will have an appointment to return to the clinic for a refill before your alarm date. Depending upon your dose, once the alarm sounds you will have from two to four days to come in and have your pump refilled. Because of the low volume in the pump, you may start to notice signs of increasing spasticity or dystonia after this alarm sounds, like before you received the pump. To avoid this alarm, always come to the CP clinic on your scheduled refill date.

2. When the battery is low – The battery in your pump has an expected life of five to seven years. The non-critical alarm in this case is called the elective-replacement indicator. When this sounds, you need to schedule a pump replacement within ninety (90) days.
3. When a non-critical pump memory error occurs – This does not affect the delivery of the baclofen, however please call us so the physician can examine you and the pump to determine the source of the error.

The **critical alarm**, is a louder, two-toned alarm (one high note followed by one low note), that sounds like a typical European police siren. The critical alarm will sound when:

1. The pump reservoir is empty.
2. When the pump has stopped working.
3. When there is a stall of the pump motor.
4. When the pump was stopped for more than 48 hours.
5. When a critical pump memory error occurred. You should be seen by a physician as soon as possible when this occurs, as it will affect the delivery of the drug.

A critical alarm needs to be attended to immediately. If you hear any alarm, or have any questions about the alarm on your pump, please follow the directions in the “How to Contact Us” section of this document.

Baclofen Side Effects, Underdose, Withdrawal and Overdose

- **Side effects of the baclofen** include constipation, weakness, headache, drowsiness, dizziness, nausea, vomiting or headache. Please let the physician know if you have any of these symptoms, as they typically can be managed by changing your dose.
- **Baclofen underdose** can happen if you go past your alarm date and your pump runs out of baclofen, if the battery is at the end of its life or if there is a kink, tear or malfunction in the catheter (tubing) of the pump. The most common **first signs** of baclofen underdose are an increase in muscle tightness or dystonia with sweating and itching without a rash. People who do not communicate often show their discomfort by becoming agitated or picking at the clothes or bed coverings. Other symptoms may include fever, an increase in the frequency of seizures (if there is a history of seizures), low blood pressure (hypotension) and confusion. Notify us immediately if you think you have signs of baclofen underdose. If the time without baclofen continues, the condition can change to baclofen withdrawal.
- **Baclofen withdrawal** is a medical emergency that must be attended to immediately. Baclofen withdrawal can result in breakdown of muscle and multiple organ failure.
- It is rare that the pump will deliver too much drug, however if this occurs, you will experience the **symptoms of an overdose**. Overdose is possible, but very unlikely, following a refill. The common signs of overdose are drowsiness, lightheadedness, sleepiness, slowed breathing, increasing weakness and loss of consciousness. If a drug overdose occurs as a result of a refill, it will happen one to

three hours after the refill. Notify us immediately if you think you have signs of an overdose.

General Information

- The baclofen has a shelf life of 180 days (6 months). Even if your alarm date is more than 6 months away, you will need to come for your refill no more than 6 months between refills to have the drug changed and your pump refilled.
- Baclofen does not typically interfere with other medications. Call us if you have a question about a medication.
- Your pump may set off the metal detector at airports, but is it not affected by air travel. Provide your pump identification card to airport security.
- It is not unusual for the pump to bulge out with coughing, sneezing or straining with bowel movements. This is normal and not a cause for concern.
- For non-emergency questions about your pump, you may call the Medtronic Patient Services line at (800) 328-0810.

How to Contact Us

- If you think you have signs of an infection, overdose, withdrawal or other medical emergency, notify us. During business hours you may call the Center for CP at (310) 825-5858. If your call is not returned quickly, please call the Luskin Clinic Line at (424) 259-6593. After hours, call the UCLA page operator at (310) 825-6301 and ask to have Dr. Oppenheim paged. If he is unavailable, you may page the team's neurosurgeon, Dr. Nader Pouratian. When you speak to either one of them, describe the situation in as much detail as you can. You will then:
 1. Receive an explanation of what may be occurring, with follow-up instructions as needed, or
 2. Be instructed to come to the next CP clinic, or
 3. Be instructed to go to the nearest emergency room. If you are instructed to go to an emergency room, make sure you bring your identification card and your most recent pump interrogation read-out. If you go to an emergency room other than UCLA and the physician is unfamiliar with an intrathecal baclofen pump or you have any concerns about the pump, you may ask the physician to call the UCLA page operator and speak with Dr. Oppenheim or Dr. Pouratian. If neither of them is available, the hospital may contact Medtronic at the number on your card. They will connect the physician with someone who knows about ITB pumps and they will get an interrogator to the physician caring for you.
 4. If you have a question about your next appointment, or other concerns that are not an immediate medical concern, you may call the Center for CP office at (310) 825-5858. The office is open 9:00 to 5:00 Monday through Thursday.