

The Sickle Cell Association of BC (SCBC), 322-104-1015 Columbia Street, New Westminster, BC, V3M 6V3. Visit us at our website at [www.sicklecellassociationofBC.com](http://www.sicklecellassociationofBC.com) or on our Facebook page – Sickle Cell Association of BC

**Pain Management Lecture:**

**Introduction:**

Speaker: Storma Mcdonald, executive director and adult patient program coordinator for the Sickle Cell Association of BC (SCBC) and is a former suicide prevention and distress line crisis counselor. The SCBC advocated in Ottawa with the SCDAC/AAFC for a national Sickle Cell Day – June 19th which is now official. She was a patient representative for the Strategic Advisory Group for the [BC Inherited Bleeding and Red Cell Disorders Provincial Program](http://www.pbco.ca/index.php?option=com_content&task=section&id=12&Itemid=116) and has gone to several of the SCDAC/AAFC national sickle cell conferences over the years and has compiled some useful information to share with others. She will be speaking about pain management from a patient perspective. She is not a doctor or specialist, but has compiled data from her amazing team of health care professionals especially her amazing pain management specialist named Dr. Pamela Squire [(604)737-7122] who has helped her to refine her pain management strategies over the years. Today she would like to share some of the things she has learned and it is her hope that you take this information to your doctors to get the care you need. Talking to your doctors or going to the hospital can be tough, especially when you do not know what to ask for – or the right questions to ask.

1. **Pain Management Protocol:**

Getting a pain management specialist can be a extremely helpful. Ask your doctor to refer you to see one – shop around to find one that you are comfortable with and does not have a lot of biases. Having good team of health care professionals that can share information smoothly is important. The following are some of the things you should discuss with your doctor in order to design several letters / documents that will aid in giving you a little more credibility when you go to emergency.

* Medication protocol (ie. medications, dosages, allergies, hematologist’s contact information as well as your pain management specialist and family doctor, etc.)
* Emergency Room protocol (I.V. instructions, oxygen, treatment plan, medication protocol)
* After care / post hospital protocol (weaning down from medications slowly and safely, nutrition, supplementation, rest and recovery, stress management, etc)
* Prevention / preventative measures (ie. Hydroxyurea, taking medications on time, regular check-ups, controlling triggers, getting current and reliable information / research, nutrition, herbs and supplements)
1. **Emergency Room Protocol:**

Here are some tips that might make the process of going to emergency go a little smoother.

* Have your doctor/hematologist write a letter with your medication protocol, allergies and instructions on it as well as the doctors contact information. Have it photocopied and bring several copies with you to the hospital just in case one goes missing. Never give them originals. These letters may help to give you some credibility and avoid being accused of being a “drug seeker”. This letter is important especially going to a new hospital or another country. Dr. Hatoon Ezzat has been giving her patients a special card that has her information and instructions on it as well. Bring this and do not lose track of it if a doctor walks off with it.
* Call in before you go to the hospital. Ask for the hematologist or hematology resident oncall and let them know you are coming in and tell them the name of your hematologist. Answer questions and tell them when you plan to arrive so they can make preparations.
* Bring some of your medications in the original bottle with you to the emergency as well, just in case it takes a long time to see a doctor. Keep track of the time you take medications as well. It is wise to always update pain management prescriptions and get them filled ahead of time, before a sickle cell crisis starts.
* Bring someone with you as a witness if possible. This person can bring food, write down the time and names of doctors that speak with you as well as what was said. Doctors will be less likely to discredit you and in cases when mistakes are made it will hold the doctor in question accountable for their behavior and treatment.
* Pack a small bag with important information/letters, change of clothes, bottle of water, book or iPod, pad of paper and a pen.
* If you have children teach them how to do all this as well, so when the transition from childhood to adulthood arrives they know what to do.
1. **Some classification of drugs:**

I, nor the SCBC, are endorsing one drug over another. Everyone’s body is different. I just want to talk a bit about whats out there. There are a lot of options out there. Speak with your doctor regarding the following drugs and there counter indications, interactions, side effects and allergies.

* NSAIDs / Anti-inflammatories (advil, ibuprofen, motrin, ketorolac, etc)

*Benefits*: pain management; aids in controlling fever.

*Drawbacks*: hard on the stomach and liver; cannot mix with other NSAIDs.

* Opioids (morphine, oxycodone, hyrdromorphone, codeine, fentanyl, etc)

This class of drugs is derived from opium.

*Benefits:* pain management.

*Drawbacks:* addictive; side effects; very controversial; stigmatized

* Canaboids (nabilone / cesamat, sativex, dronbinol/marinol/syndros, epidiolex, etc)

This class of drugs is derived from marijuana / cannabis. As of Oct 17th, 2018 Cannabis is legal in Canada according to the Cannabis Act.

*Benefits*: pain management; nausea and vomiting; said to increase pain threshold (this may cause a problem if you don’t go into hospital quick enough, so stay in touch with your hematologist.

*Drawbacks:* very controversial; possible addiction; expensive; your doctor may or may not be supportive with this classification of drug, *especially in the emergency room*. There are a lot of stigmas attached to this class of drug. It is best to ask your doctor what they think of this classification, before asking for it. See if your doctor has strong opinions or bias for or against this classification. Do this at your own risk. Just because this class of drugs is legal in Canada does not necessarily change people perceptions about it. Also, you cannot take these drugs with you if you travel. Have a special letter / medication protocol letter with you when you travel and avoid putting this class of drugs on it, just in case. This classification of drugs may be illegal in other countries. Do your research.

* Other drugs (Tylenol, aspirin, etc)

*Benefits:* controlling fever; some possible pain management

*Drawbacks*: pain management could be minimal

* Herbs and supplements (*L-glutathione*, L-arginine, L-glutamine, L-carnitine, *prickly ash/zanthoxyllum*, red root/ceanothus, carao fruit, baobap, moringa, *folic acid*, vitamin D, magnesium, probiotics, piracetam, thiocyanate, nitric oxide, etc.)

*Benefits*: possible preventative measures.

*Drawbacks*: not a lot of pain management; not a lot of hard scientific data on some of these products; you may have possible side effects, interactions and counter indications with other drugs you may be taking; expensive/not covered by medical; controversial. It is best to find a professional herbalist and/or naturopath to talk to – talk to them about side effects, counter indications and interactions with other drugs you may be taking. Also, get hard scientific data / medical journal articles from credible sources, then share all this information with your doctors.

1. **Medication Protocol**: When talking to your doctor or pain management specialist it is important that you have a discussion about the levels of pain and what to take for each level when you’re at home*. It is extremely dangerous to ignore a sickle cell crisis or to wait too long before managing it.* When in doubt, go to the hospital and/or talk to the hematologist on call at your hospital. *If you are having acute chest syndrome – do not wait – go to the hospital immediately as acute chest syndrome can be lethal.*
* Level 1 pain – mild pain
* Level 2 pain – moderate pain
* Level 3 pain – moderate / severe pain
* Emergency room – severe pain you can’t take care of at home
* Post hospital – ask your hematologist and pain specialist to create something for you so that you recover and come off / wean down from any medications slowly and safely.
1. **Q&A**
2. **Pain Management Support Groups:**
* Barb Boyd will speak about the organization she works for (People in Pain Network) and the pain management support groups /workshops around the city.
1. **In closing:**
* FunDrive fundraiser
* SCDAC/AAFC’s sickle cell conference in November 8th-10th in Toronto
* Thanks to everyone for attending