

Hello Colleagues,

My name is Wendy Moss, and I am a VAC Nurse at BCCH. I am on the Board of Vascular Anomalies Canada (VAC-AVC) and my bucket of work is Patient and Family education. This is how I was able to reach out to you, although.... some I knew from ISSVA Amsterdam and ISSVA Australia and from conversations where all we had was each other, navigating a tough situation!

At VAC-AVC we **want to build a database of pamphlets, videos and resources that we can have available for download by families.** We have been given funding by Pfizer Canada to put this into action.

I am writing to ask for **10 minutes** of your time **please.** **My ultimate goal in writing you is to have you brainstorm and provide me with questions that a patient or family might ask to better navigate and understand their care.**

**Background.**

- We know that your individual clinics will give specific information and advice suited to needs of patient's, families and your clinical workflows. And there is already a lot of information available on the Web about different diseases and their treatments. **We don't want to re-invent these.**
- What we hope to do is **equip families and patients with the power to ask questions and to navigate their health care** as a patient with a diagnosis that is usually not well known.
- As a nurse, know what patients and families ask about most often AND what is difficult for them to navigate in your city or province.

**My ask is that you provide prompting questions or statements that we can eventually put into an online pamphlet or resource. To get the ball rolling, I have started with Sirolimus. FEEL FREE TO add questions to this topic and MAKE your OWN topic up.**

**TOPIC: Sirolimus**

*NURSING PERSPECTIVE: What would patients benefit from knowing regarding care and management with sirolimus, that the attached pamphlet would not address?*

e.g., How long will I be on it?

e.g., What are the long-term side effects of it, or do you know?

e.g., How would MD decide if Sirolimus is working or not?

e.g., I see that blood levels must be monitored regularly. How does this work? Is there a lab close to my home that can draw blood from my child who has needle phobia?

e.g., When would it be changed or discontinued if it doesn't seem to work?

e.g., Can I actually get Sirolimus from my local pharmacist if my child is too small to take a tablet form?

e.g., What are all the ways to disguise the bad taste of Sirolimus?

e.g., What are all the different ways I can get help paying for such an expensive medication? And What paperwork is involved in applying for and maintaining the funding for this?

e.g., When does the Standing Order for blood work expire at my local lab, and how to I plan ahead so that the order for blood work doesn't expire?

**TOPIC: *Compression Garments***

NURSING PERSPECTIVE: *What would patients benefit from knowing regarding care and management with garments?*

e.g., What is the cost to me for each pair of garments, and what help can I get paying for them? Ask if there are local charities, benefit providers or funding sources

e.g., How long does a pair of garments usually last?

e.g., When can my child stop wearing garments?

e.g., Why do I hand wash them? What soap do I use?

e.g., If I get a prescription, will my benefits pay for them?

e.g., Are there local charities that can help pay for garments, like Variety Club or War Amps or others near me??

e.g., Can you please write a prescription for TWO pairs a year? (One is to wear while the other is hanging to dry; they only last 6 mos. each before elasticity starts to wear out).

e.g., Can you explain why I need a custom garment and why I can't get my child one over the counter or off the shelf?

e.g., Will they ever be able to get non-custom garments that are cheaper?

e.g., What is the difference between dynamic compression garments for daytime use, and nighttime compression?

e.g., Why is one kind of garment like clothing and the other is a wrap?

e.g., Is there a garment fitter near me who understands how to fit children for custom garments?

e.g., is there another option for nighttime garments that isn't

**TOPIC: *Infantile Hemangiomas***

Questions to prompt families:

1. When will this go away?

2. If we treat, is it all going to go away?

**TOPIC: *Venous Malformations***

Questions to prompt families:

1. Is this going to cause any long-term issues if we don't treat it now?

2. When it gets little clots in it, are those going to move to other parts of my body?

3. Are long term NSAIDS going to cause any harm?

4. If it is hit, could it cause bleeding?

**TOPIC: *Lymphatic Malformations***

Questions to prompt families:

1. Who do I call when the lesion swells?

**TOPIC: *Sclerotherapy***

1. How long will I be off work/school?

2. How many treatments will I need?

3. Will a hospital admission be required?

Thank you for your almost non-existent time!!!!

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