

BONDED BY BLOOD | BROTHERSHEALTHCARE.COM | FIRST QUARTER 2019

BECAUSE YOU MATTER TO US.



In 2019, may we treat ourselves with the compassion and love that we reserve for our closest family and friends.

Each new year, we reflect on ways we can improve our lives, our health, our families. Then, we are confronted with endless tasks and limited time which makes goal-setting overwhelming.

How do you find time for everything you feel is necessary and important? This year, instead of trying to squeeze more out of each minute, consider what tasks you can give up or give away. Perhaps this year you can give yourself permission to do **less** and still acknowledge, "I am enough."

-Jessica Steed, Editor

UPCOMING EVENTS

HFSC Industry Forum Los Angeles, CA January 19, 2019 Nevada NHF Wine Fest Las Vegas, NV February 8, 2019 **CCHF Surf and Turf Event** February 9, 2019 Sacramento, CA EmPOWERment Forum & Salsa Challenge Burbank, CA February 23, 2019 AHA Arizona Hemophilia Walk Phoenix, AZ February 24, 2019 AHA Bleeding Disorders Month Kick-Off Phoenix, AZ March 8, 2019 Nevada NHF Spring Education Fest Las Vegas, NV March 16, 2019 **HASDC Advocacy Forum** San Diego, CA March 16, 2019 Hawaii NHF Ohana Education Weekend March 22, 2019 Honolulu, HI **HFSC Women's Retreat** San Marino, CA March 23, 2019 **HOPE for Hemophilia Crawfish Boil** March 23, 2019 Baton Rouge, LA LAHF Family Day in the Park Baton Rouge, LÁ March 24, 2019 NHF Washington Days Washington, D.C. March 27-29, 2019 **HFA Annual Symposium** April 4-7, 2019 San Diego, CA

For more info, contact your local chapter or info@brothershealthcare.com

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In this issue, pharmacist and nutritionist Eslam Omar describes the history of oils and explains potential interactions of specific oils with bleeding disorders. As always, before using essential oils, please consult your healthcare provider. In our next issue, look for more detail about the benefits and therapeutic uses of essential oils.

ASK A PHARMACIST

WHAT ARE THE DO'S AND DON'T'S OF

By Eslam Omar RPH, MPH, Pharmacist, Nutritionist

Across several ancient civilizations, the use of essential oils can be traced for cosmetic, healing and medicinal uses. Ancient Egyptians used certain essential oils like peppermint, cedar, thyme, chamomile and lavender to enhance body odors, soften the skin and heal wounds. Evidence of this has been found on papyrus dated back to 1500 BC.

Ancient Chinese traditional medicine explains that there are 3 types of essential oils: High Notes which are used to treat the immune system - *Wie Qi* (e.g. eucalyptus, mint and citrus); Medium Notes used to enhance the digestive, cognitive and circulatory system - *Ying* (e.g. oregano, caraway and rosemary); finally, Base Notes which are believed to treat stress and pain - *Yuan* (e.g. frankincense).

While essential oils have been used across the globe, it was the Arabs and Persians who mastered the art of isolation and distillation from herbal plants. Avicenna, the Persian physician, carefully documented the process in his famous book, The Canon of Medicine, which later was used as medical reference in Europe as late as the 18th century.¹

Unfortunately, modern scientific evidence-based medicine tells us little about the benefits and side effects of essential oils, especially concurrent with medical conditions like hemophilia. So, for the purpose of this article we will focus on essential oils that should be avoided by bleeding disorders patients. As a general rule, people with bleeding disorders should avoid ingestion of essential oil. The safest method to use essential oils would be topically. Ingestion would increase the risk of side effects and medication interaction. Here are some of essential oils that possess high bleeding risk and should be avoided;

Wintergreen oil is used as an analgesic and anti-inflammatory, usually added in topical preparations for joint and muscle pain. It contains methyl salicylate which has powerful analgesic properties, but also is

SCHOLARSHIP Q2

By Veronica Diaz, LCSW

If you have a bleeding disorder, there may be scholarships for secondary education or trade-school open to you.

Who is eligible?

Look carefully to see if you are meet these criteria before you apply for a scholarship:

Diagnosis - Most bleeding disorders scholarships are for people with a specific diagnosis like hemophilia or Von Willebrand disease (VWD), and sometimes family members are also eligible.

Age - Some are only for high school seniors, but others accept current college students.

Educational Program - Most are for university or community college, but others

include technical programs.

Geography - Some scholarships focus on specific states or regions.

Citizenship - Undocumented students cannot legally receive any federally-funded student financial aid, including loans and grants. However, some private scholarships do not require applicants to be US citizens.

What do I need?

Good grades are only part of the equation. Application reviewers look for well-rounded students with thoughtful essays, recommendations, and volunteer work. Financial need may be considered as well.



When do I apply?

January - July are the most common deadlines for scholarships. It doesn't matter if you are the first to apply, just get your application in by the deadline!

Where do I find scholarships?

HFA.org, NHF.org, needymeds.org, maldef.org, goldendoorscholars.org, and

USING ESSENTIAL OILS FOR BLEEDING DISORDERS?

considered a blood thinner. Furthermore, it will alter the effectiveness of factor VIII and factor IX infusion. Therefore, it should not be used by hemophilia patients. Products which contain methyl salicylate include Bengay, Salonpas and other similar muscle and joint creams and gels.

Birch oil is present in several skin care products and is sometimes found in facial toners. Birch oil also contains salicylate compounds, like Wintergreen oil, and therefore should be avoided by hemophilia patients and those with other inherited blood disorders.

Garlic, leek and onion oils, usually taken orally, are used to enhance the immune system and are also praised for their anti-inflammatory properties. However, they are sometimes used for blood thinning.² Thus, hemophilia patients should be cautious while using garlic and only consuming a normal amount in foods is recommended.

Helichrysum oil is used for its skin sooth-

ing and moisturizing effect. It is common among Mediterranean countries. The name is derived from two Greek words meaning sun and gold referring to the plant flower. Although the flowers may be attractive, its oils are anti-coagulant³, and so are not recommended for hemophilia patients.

The following essential oils have moderate risk on bleeding-related conditions. Ingestion of these essential oils should be avoided and should only be used topically with caution; Anise, Basil, Bay, Bee Balm, Cinnamon, Clove, Fennel, Oregano and Thyme.

In conclusion, humans have benefited from the wonders of nature for thousands of years. Several civilizations throughout the world and over history have praised the importance of essential oils. They continue to use essential oils for cosmetic and medicinal purposes as well as for spiritual healing. However, limited research has been conducted regarding the use of essential oils and so little is known about how safe they actually

are. Most scientific recommendations to bleeding disorders patients in specific, are to avoid them especially those with high bleeding risk.

¹ McGinnis, Jon (2010). Avicenna. Oxford: Oxford University Press. p. 227. ISBN 978-0195331479.

² Effect of diallyl trisulfide-rich garlic oil on blood coagulation and plasma activity of anticoagulation factors in rats. Chan Kc, Yin Mc, Chao WJ, Food Chemistry and Toxicology, 2007, Mar;45(3):502-7.

³ Uses and Abuses Of Plant-Derived Smoke: Its Ethnobotany As Hallucinogen, Perfume, Incense, And Medicine," Oxford University Press, July 15, 2010





scholarships.com all have lists of scholarships for bleeding disorders. Scholarships may be renewable and range from \$1,000-\$6,000 with many around \$2,000.

How do I apply?

Start early! Use local resources and ask for help. Develop a plan to spend a few hours each weekend working on scholarship applications.

Contact your local chapter or Brothers Healthcare for help locating bleeding disorder scholarships.

Look for a Brothers Healthcare Scholarship coming soon!

SMART GOALS BY

In addition to giving yourself permission to do less in 2019, perhaps there are habits you'd like to start or other goals you want to set. Often these changes require focused effort. So, if you do set goals, make them SMART goals; because a goal without a plan is just a wish!

Below are some suggestions on how to turn wishes into SMART goals.

Wish: "I want to be more active."

SMART goal: "I will walk my dog for one mile at least three times a week after dinner."

Wish: "I want to give back to the bleeding



disorders community." **SMART goal:** "I will attend a chapter event quarterly and introduce myself to someone new each time."

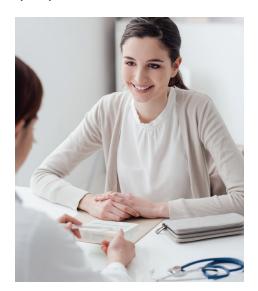
Wish: "I want to have fewer bleeds this year." SMART goal: "I will set up phone alerts to remind me to do my treatments and share my progress with my doctor."

You may gain accountability if you tell a friend about your goals but remember to be kind to yourself as you work toward them.

Source: https://www.mindtools.com/pages/article/smart-goals.htm

VWD CORNER: HOW TO ADVOCATE FOR TREATMENT

By Gaby Zamora and Jessica Steed



For some people with VonWillebrand's disease (VWD), it's a struggle to get the treatment they need for their bleeding disorder. As diagnosis and awareness of VWD increases, more doctors are treating VWD patients with a variety of medications, including factor replacement therapy. Still, many people with VWD do not have access to the treatment they need and struggle with nosebleeds, joint or muscle bleeds, and for women, heavy periods.

If you have a bleeding disorder like VWD, you may want to ask your doctor to start or change treatment. However, before you talk to your doctor about treatment options, do your research, be prepared, and engage assertively to advocate for yourself or your child.

Do Your Research

Is your bleeding abnormal? Start with a self-assessment for both men and women at https://letstalkperiod.ca.

What products and treatments are available for my condition? Talk to your specialty pharmacy about what products are indicated for your condition. Be sure to ask how the products are stored, administered and about possible side effects. Know if your specialty pharmacy can deliver all medications and provide a nurse to train you to give yourself treatments if needed.

Be Prepared

Track your bleeding: Use a journal or an app like Sisterhood from Hemophilia Foundation of America (HFA) or Microhealth to log your bleeds to share with your doctor.

Have confidence: Your doctor is your healthcare partner. In fact, he or she works for you! Recognize that doctors are busy and have varying levels of experience with VWD, but sincerely want to provide great medical care.

Stay connected with a supporter or advocate: You may call or text this person for encouragement or questions before your appointment. Use their expertise to guide you in advocating for yourself or child.

Engage Assertively

Show and Tell: Explain your symptoms to your doctor to demonstrates how your bleeding disorder affects your life. Show photos of bleeds or bruises, share bleeding logs, describe activities you can't do because of VWD.

Ask and Listen: If you know what treatment you'd like, ask for it. Otherwise, ask for a list of products from your doctor. Remember, you and your doctor are working together to keep you healthy. Be sure to thank him or her for listening to your experience.

Clarify and Advocate

Ask questions to understand your doctor's decisions and your treatment plan. Try to negotiate for the treatment you want or request a free trial from a manufacturer. If you don't get the treatment you expected, consider seeing another hematologist for a second opinion.



In the end, it can sometimes feel like a fight to get the treatment you need for yourself or your child. However, if you use your resources and communicate clearly with your doctor, you increase your chances of getting great medical care. Reach out to your Brothers Healthcare rep if you have questions or need support.

ASK US! Call or email us with any questions you have about sports, life, relationships or your managing your medical condition and we will lend our expertise to help you in any possible way.

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