

# Algorithm for the Diagnosis and Management of FVIII Variants in People with the Potential to Menstruate

Amber Federizo<sup>1</sup>, DNP, Danielle Nance<sup>2</sup>, MD, Ashley Gregory<sup>3</sup>, Kimberly Haugstad<sup>3</sup>

1) Octapharma, USA 2) Banner MD Anderson, AZ 3) FAIR Coalition, CA

## OBJECTIVES

The National Hemophilia Foundation's State of the Science Working Group 4 has published 44 key needs of people with the potential to menstruate (PPM) and called for more robust data collection on these issues.<sup>1</sup> PPM account for only 15.3% of the participants included in the largest registry for FVIII deficiency in the US despite the potential to inherit their condition from both parents.<sup>2</sup> The US is behind other developed countries in identifying and treating bleeding disorders in PPM. To accomplish the goals of data collection and address these gaps we obtained input from clinicians and PPM with FVIII deficiency to develop an introductory algorithm to guide clinicians in managing PPM across the lifespan.

## METHODS

We collaborated with Females are Important to be Recognized (FAIR) Coalition for women and girls with bleeding disorders and consulted with adult and pediatric hematologists via virtual discussions to create an algorithm that covers different, age-specific, elemental needs of PPM. The algorithm is flexible and adaptable to evolving research and clinical practice. An initial road map to facilitate change.

## SUMMARY

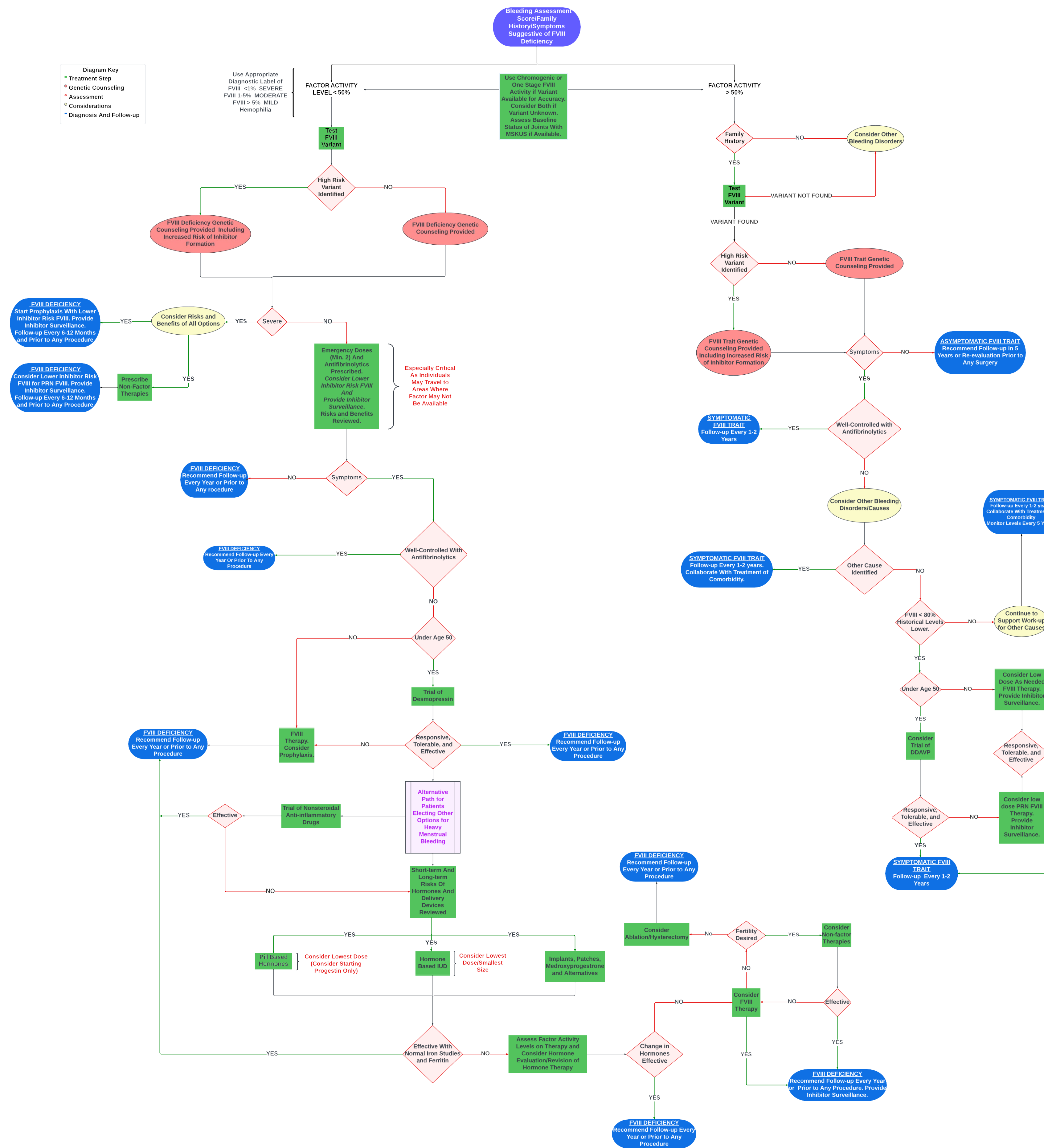
Discussions revealed that awareness efforts have been insufficient to translate research needs into clinical efforts to obtain reliable data on PPM. PPMs report abbreviated attempts to evaluate or monitor their conditions due to outdated stigmas and discrimination surrounding their sex and bleeding symptomatology. Clinicians reported a lack of available resources to guide specific clinical decisions or pathways to evaluate effectiveness over time.

## CONCLUSIONS

A first of its kind algorithm of care for those with FVIII deficiency, genetic variants, and special considerations for PPM was developed along with additional recommendations for PPM who are no longer able to menstruate. Next steps will be to validate the tool in practice and obtain objective data around its effect on outcomes, with an emphasis on quality of life.

References:

1. Ragni MV, Young G, Batsuli G, et al. Building the foundation for a community-generated national research blueprint for inherited bleeding disorders: facilitating research through infrastructure, workforce, resources and funding. *Expert Rev Hematol.* 2;16(S1):107-127.
2. American Thrombosis & Hemostasis Network. *ATHNdataset REPORT.* Winter 2022.



## ADDITIONAL CONSIDERATIONS

Normal Ferritin must be included as a metric in evaluating effectiveness of therapy in addition to ABR.

Hemostatic dental care provided at all ages to prevent bleeding/complications.

Hemostatic care plan provided to address potential bleeding in cervical screenings (every 3 years) in women aged 21-65.

Hemostatic care plan provided starting at age 50 to reduce the number of mammograms resulting in hematomas/excessive bleeding related to tears/compression of the breast tissue during screening.

Provide sexual health education, pregnancy planning, and hemostatic plans of care to monitor and treat bleeding arising from sexual activity, pregnancy, and prevent postpartum hemorrhage.

Provide education at age 45-49 (standard risk) regarding the need for colorectal cancer screening. Advise that changes in hemorrhoid bleeding should always be reported and have a management plan. Provide care plans to address bleeding related to colonoscopy especially when polyps taken.

Provide education and consider osteoporosis screening starting at age 50.