

# Achieving more Rapid Treatment through a High Trust Network

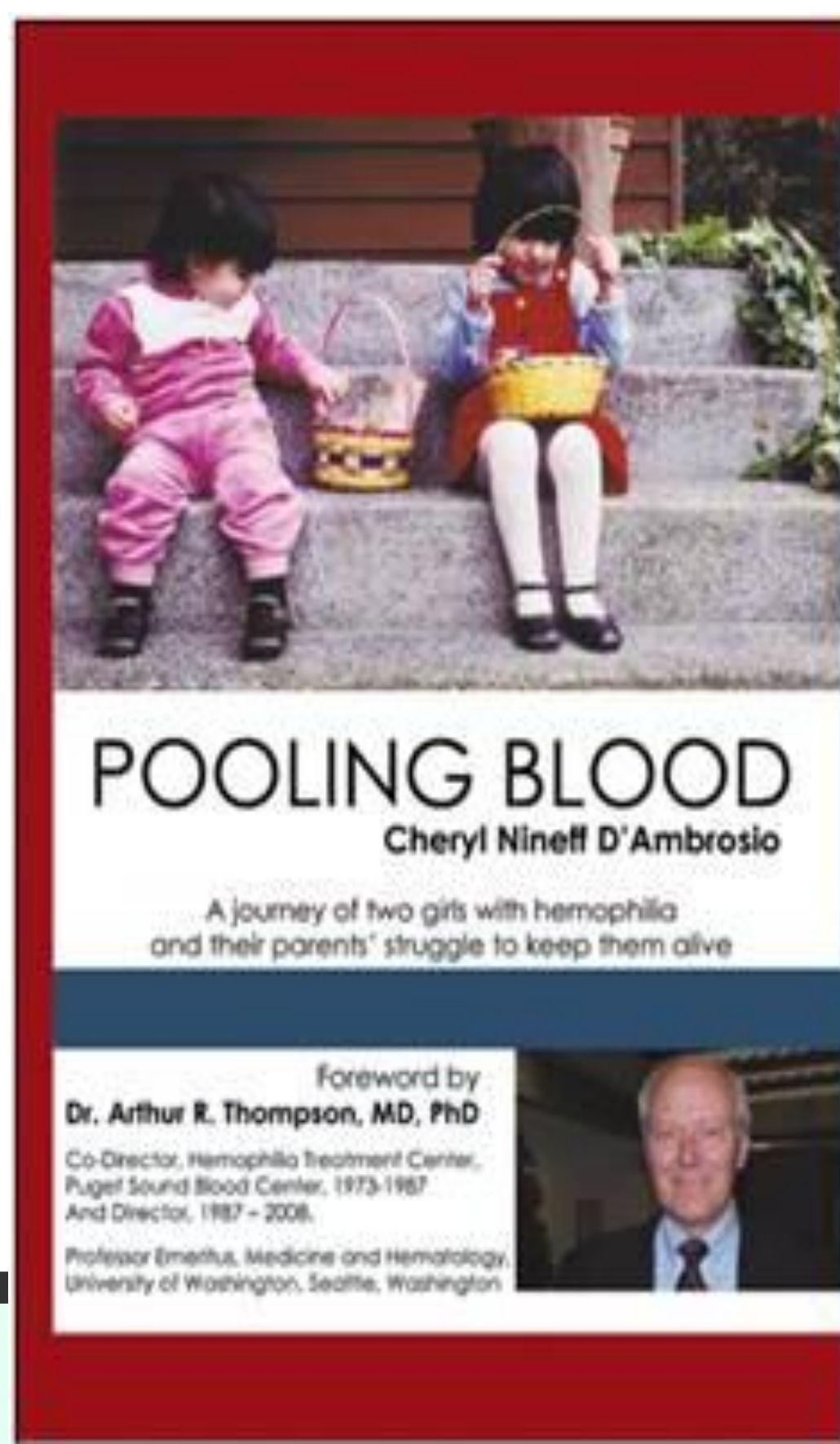
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Hemophilia 2010 World Congress

Abstract

Buenos Aires, July, 2010

## MyGirlsBlood

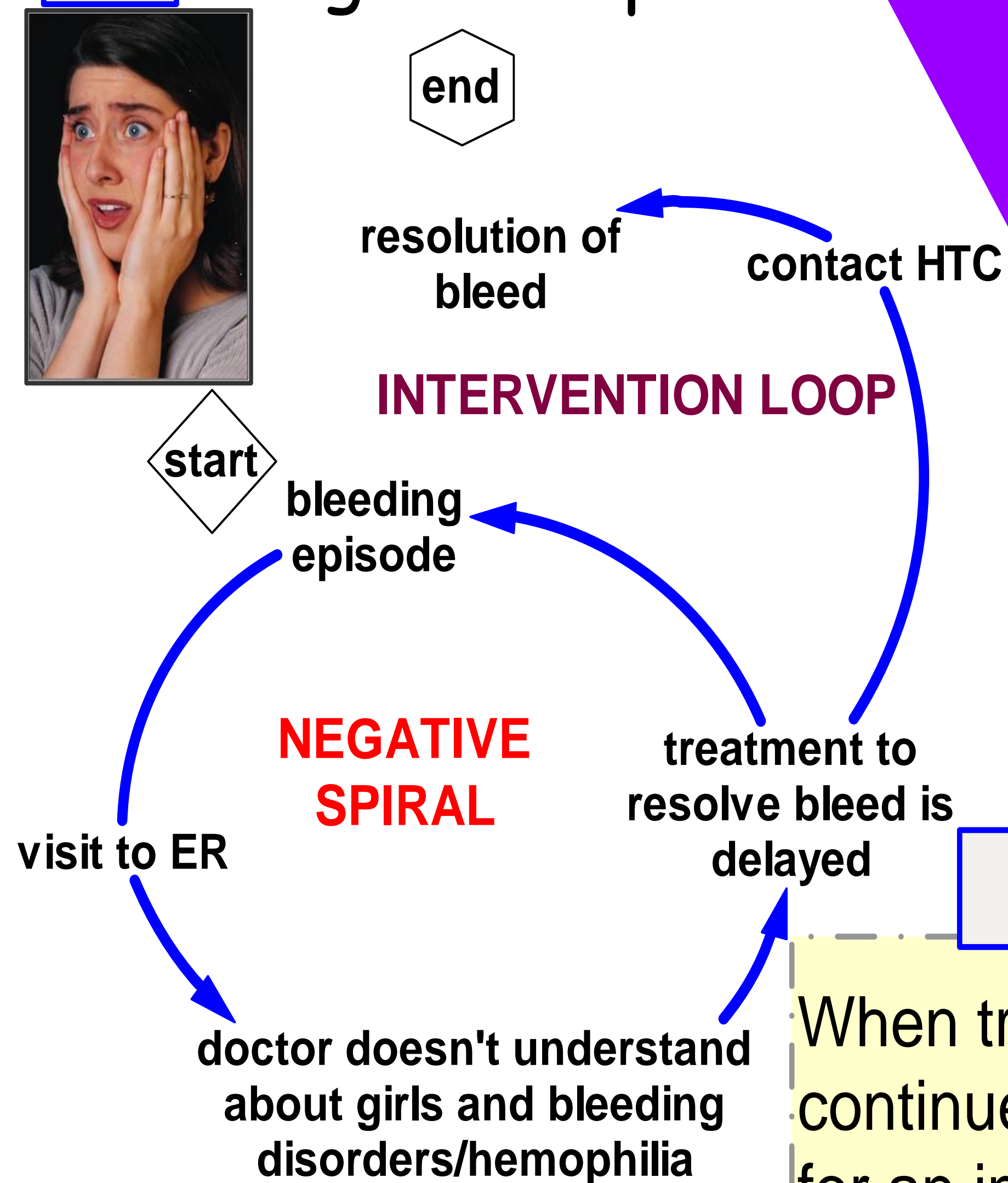
International social network nonprofit & charity 501 (c) (3)



### 1 ABSTRACT

- Memoir covering thirty-year time span, *Pooling Blood*, (D'Ambrosio, C.N. iUniverse, 2010)
- Bleeding episodes of two girls with severe factor V deficiency (only FFP; no factor products avail.)
- Hospital physicians routinely ordered unnecessary tests, delaying treatment
- Interpersonal dynamics improved when Puget Sound Blood Center's HTC became involved
- Decreased time for administration of FFP from up to twelve hours to under two to three hours
- Developing key relationships prevents delays in service delivery

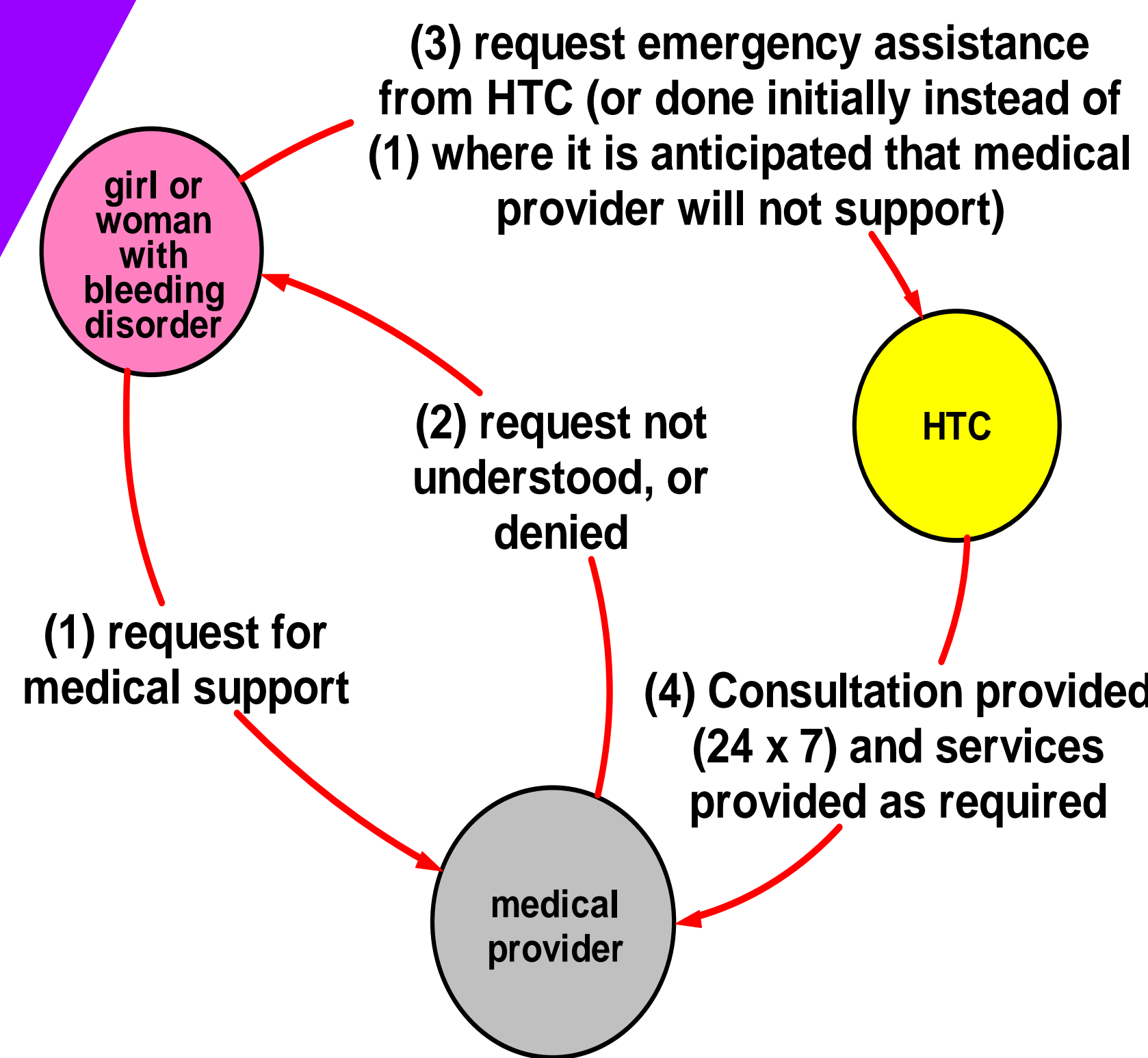
### 2 Negative Spiral



### 3 Challenges

- Doctors are trained to diagnose a problem before treating it.
- Few cases of girls and women with bleeding disorders.
- Developing relationships is considered soft-stuff.
- Standing orders are not always acknowledged

### 5 HTC Intervention



#### HTC Services

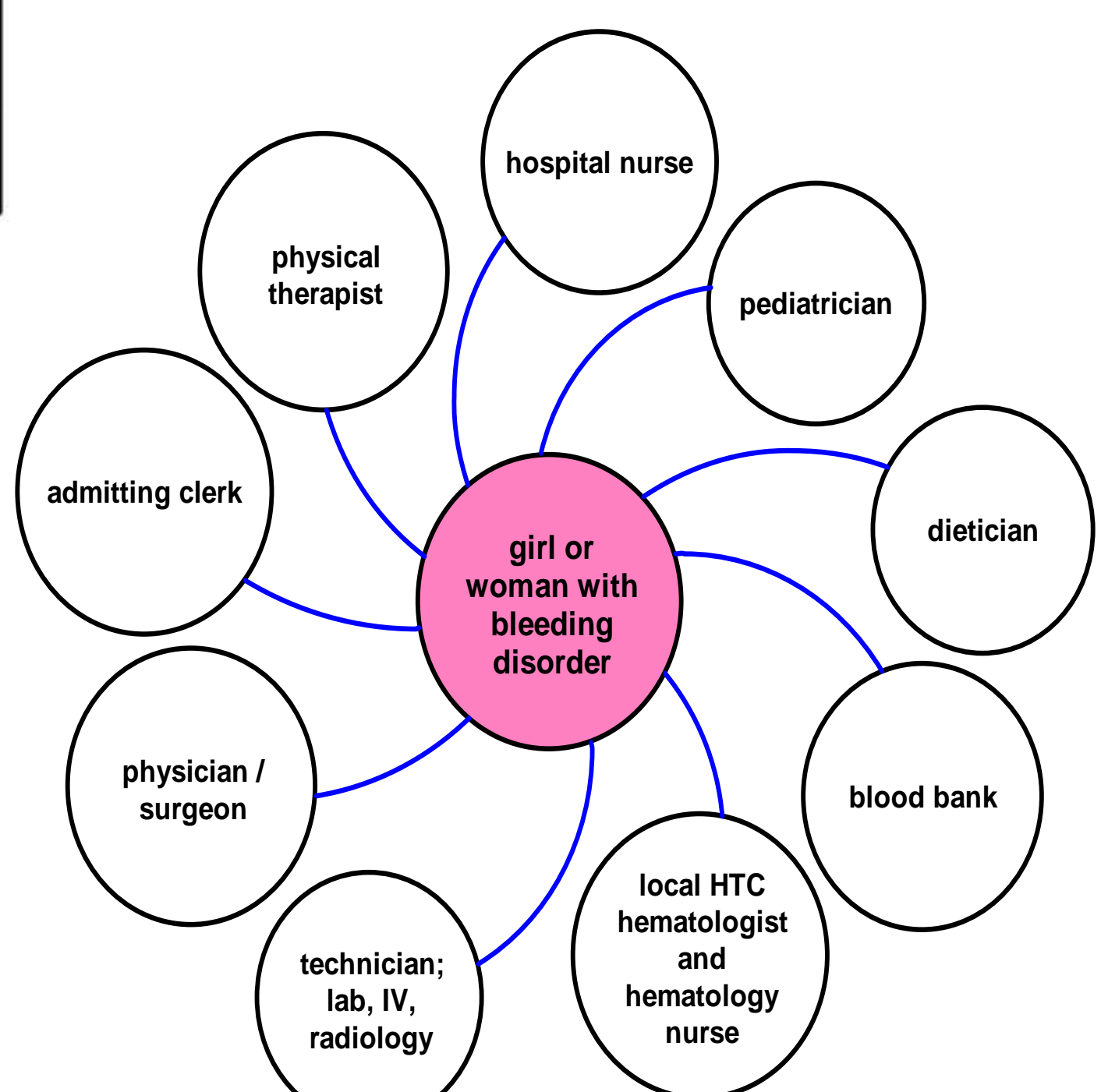
- Medical assessment and treatment of bleeding episodes
- Diagnostic testing and specialized coagulation studies
- Resource coordination
- 24-hour triage and consultation
- Home infusion training
- Genetic counseling and carrier testing
- Clinical trials
- Individual and family education and counseling
- Distribution of FFP, factor and clotting concentrates

When treatment is delayed, and standing orders ignored, bleeding continues, creating a vicious cycle. One way to stop the bleeding is for an intervention from a Hemophilia Treatment Center. This results in more rapid treatment, thus interrupting the negative spiral.

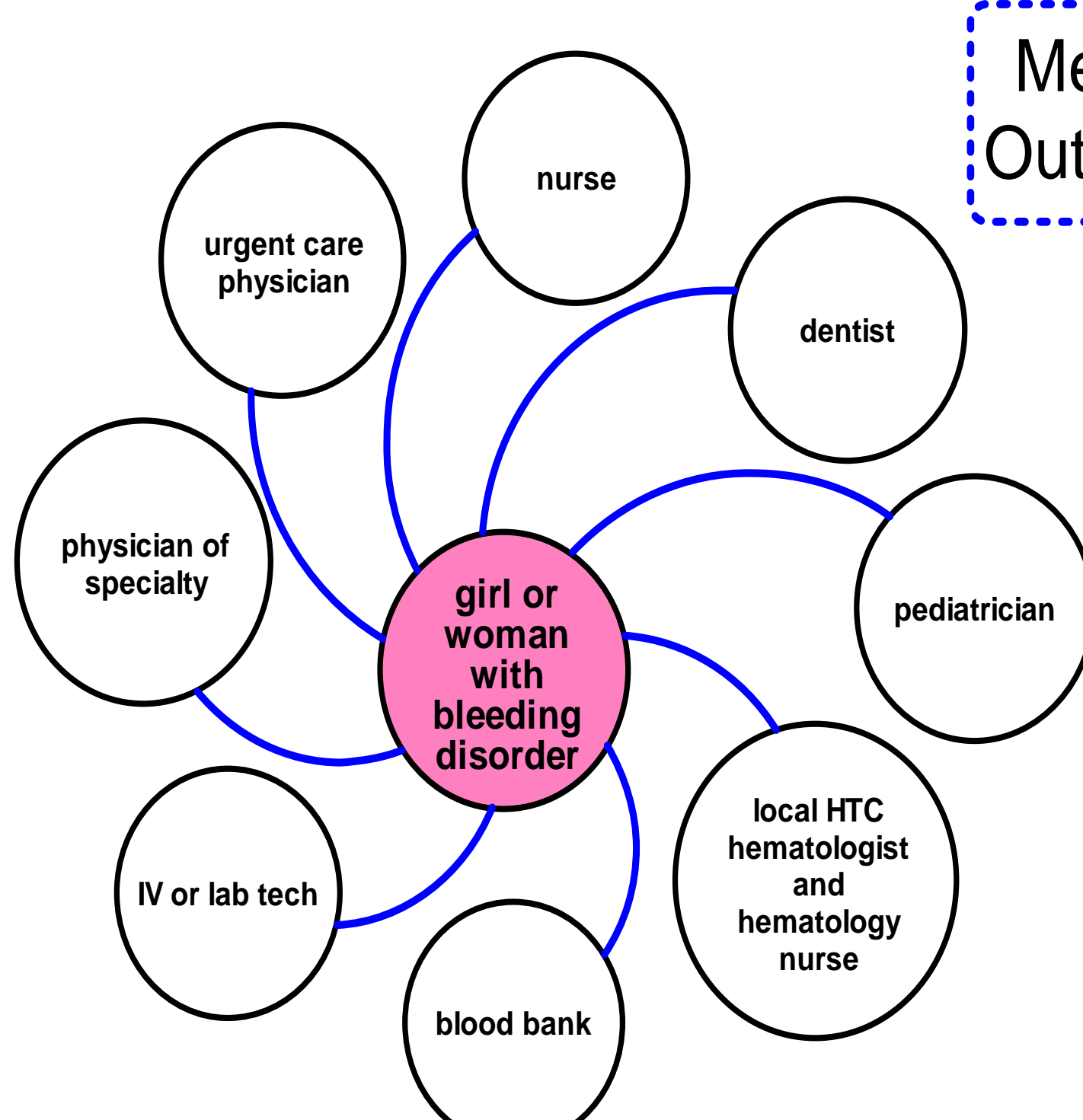
6 People with bleeding disorders must become proficient in developing successful relationships with many people in many roles



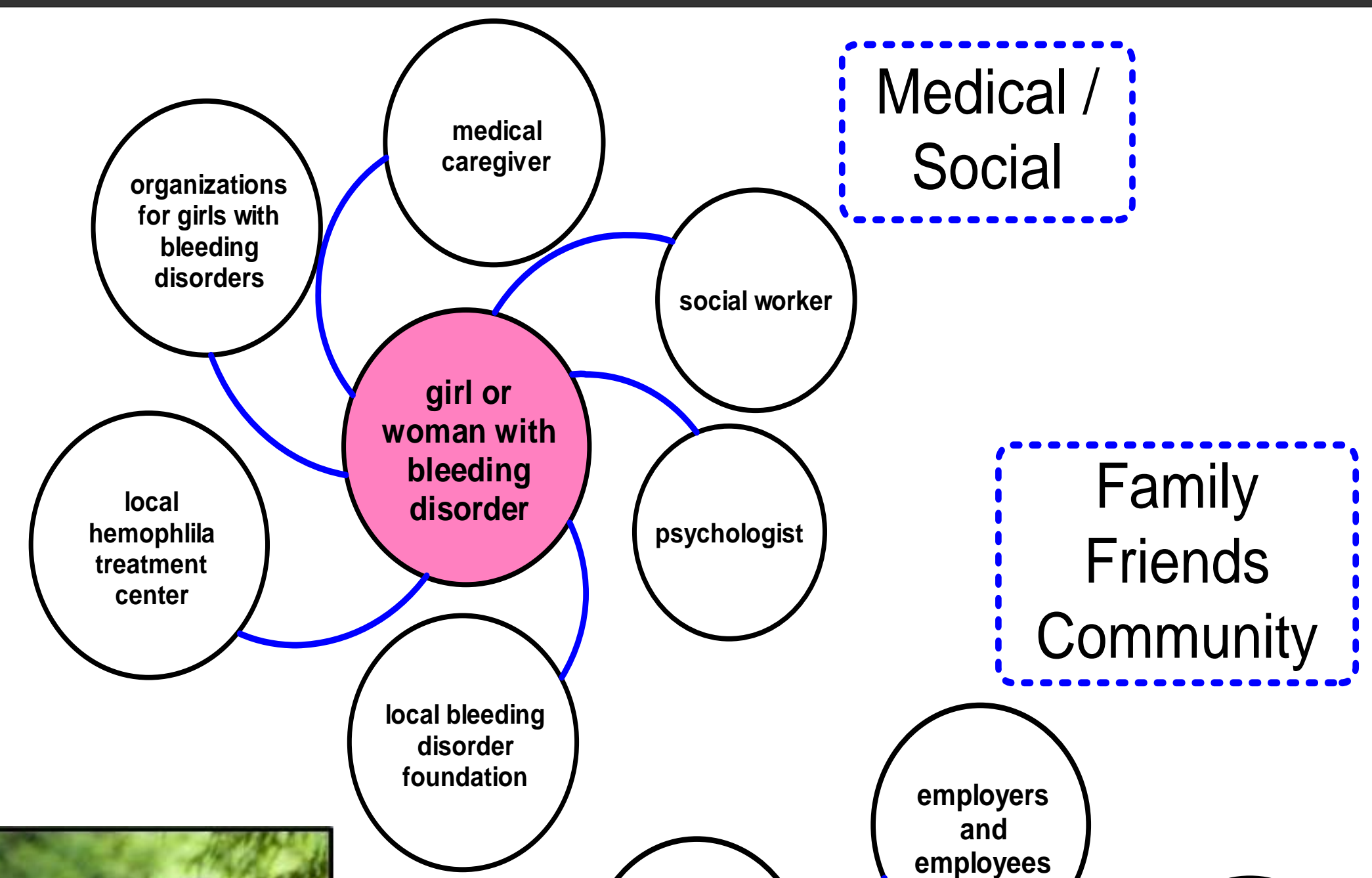
Medical / In-patient



Medical / Out-patient



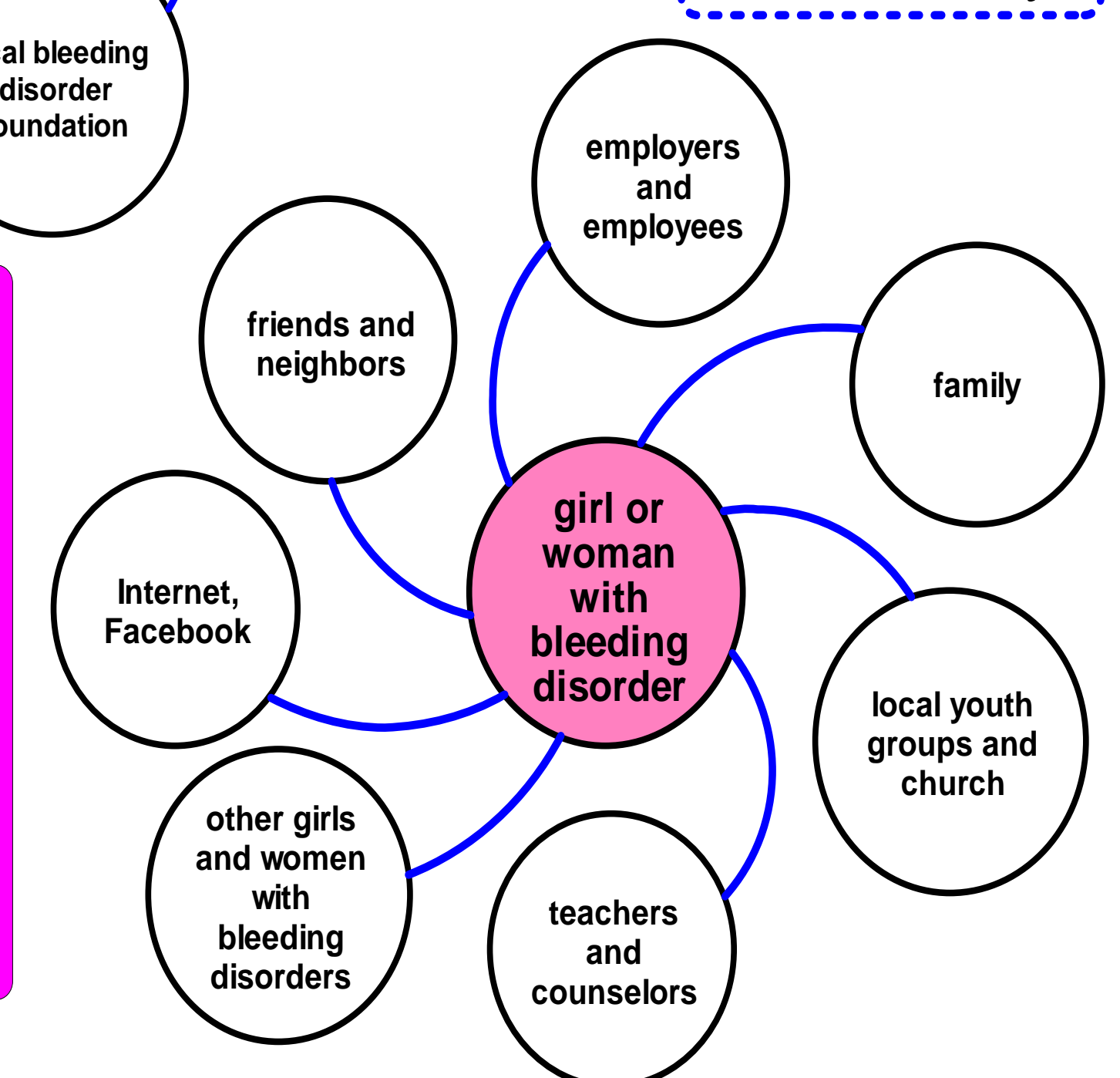
Medical / Social



Family Friends Community



7 Prepare a "medical resume" including specific information for each role (\*)



\* Templates available: www.mygirlsblood.org

Write it down and keep it with you in case you cannot speak for yourself. Establish a standing "treatment plan" with your ER, if possible.