

Online Anthology of Individual Experiences by Girls and Women with Bleeding Disorders

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Abstract

The complexity of the signs and symptoms of girls and women with bleeding disorders (WWBD), and the life-long consequences of their bleeding disorders, surpasses available scientific data.

Physicians (including hematologists, dentists, primary care physicians, surgeons, gynecologists and obstetricians), other care providers, and WWBD themselves, must become educated in recognizing the uncommon signs and symptoms of bleeding disorders in females and become aware of the potentially life-threatening risks associated with undiagnosed patients.

The online Anthology Project of MyGirlsBlood (www.mygirlsblood.com) began in 2009 and chronicles a variety of WWBD life experiences, written first-hand by the women themselves. Authors include women living in the Philippines, Austria, Latvia, Kenya, India, Iran, Canada and the USA. Each quarter, new writings are added into the project.

Personal narratives describe women who suffered from uterine bleeding lasting 18 months post childbirth, abnormally heavy menstrual periods with a duration of fourteen days, cerebral hemorrhages, dental extractions which resulted in prolonged bruising, complications following a tonsillectomy, symptomatic carrier bleeding episodes, and the life experiences of generations of women, grandmothers and mothers who were never diagnosed or provided treatment plans.

The Anthology Project also includes stories that detail the complex emotions and reactions of WWBD such as grief, anger, guilt and shame.

An index of women, who have participated with MyGirlsBlood, called Roll Call, reveal 18 types of bleeding disorders across an international network of over 150 women.

Better understanding of the lives and needs of WWBD will lead to improved educational programs for WWBD across the globe. Providing an on-line accessible learning tool for the medical community, other care providers and WWBD has been helpful in teaching others about WWBD.

Stories and poems written by WWBD show ways in which these girls and women have learned not only to cope, but to flourish.

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



Reflections from a hospital room
by Andrea - The Philippines
I am sitting here in my daughter's hospital room, watching her as she sleeps, pondering on her future and the future of other Filipino "bleeders" like her.
With the election fever high up in the air, I wonder what difference the incoming elected officials will bring to the very sick public health system.
Davao, Maguindanao
Health care is always like a luxury, especially for the poor. Also known as "royal disease," it is so rare that it is affected by it. Rumors have it that Hemophilia is because of the monarchy.

Meet Tova
Tova - Israel
I'm Tova, I'm nearly 17 and I have a bleeding disorder that I found out about when I was 12. I've spent most of the last 5 years in bed at home or at hospital - not doing all the things that normal, healthy teenagers do, like going out with friends to the mall or to the beach and going to school. I take tranexamic acid four times each day and I get DDAMP at the hemophilia center twice a month. I have many bruises and I'm constantly afraid of falling or cutting myself.

The Joy of Giving
Tova - Israel
I began volunteering by caring for a three-year old boy named Jonny. He sits in a wheelchair and he sits in a wheelchair on the floor where he sits with him. I spent time with him, hemophilia center twice a month. I have many bruises and I'm constantly afraid of falling or cutting myself.

The Deck of Cards
by Christina - Linz, Austria
My name is Christina and I was born in Austria on September 1995. I was diagnosed with afibrinogenemia when I was 3 days old and I want to share my story with you with the help of my favorite quote:
"Life consists not of having good cards but in playing those you have well."

Her Blood Runs Through Their Veins
How a bleeding disorder restored one family's connection with their ancestors.
by Virginia - New York, USA
"The patient was born in Indiana County, Pa." Thus began the record of the medical history of this widow of a civil war soldier. A few months before her death, Mrs. Elizabeth Jane McIntyre Jeffries was admitted to the hospital. Jane McIntyre Jeffries had the inspiration (or the order) to stand next to him. When he died, she made noise of happiness.

Story of my pain
by Monika, Mathura, India
Original writing in Hindi
Translated in English by Priyanka, Ambassador, India
My name is Monika. I was born in Mathura, India on April 10, 1992. The midwife who assisted my mother's delivery accidentally scratched my tongue by her nail while my tongue continued bleeding the whole morning I was taken to a nearby village hospital. I died.

Planning Is Essential
by Linda - Tallahassee, Florida
"Pass me the hippopotamus," I demanded at breakfast.
"The what?" Robin said.
Frustrated I pointed, "You know, that thing on the table."
"You mean the banana?" She looked more concerned than confused. In the thirty years we had been companions, she had seen me recover from many illnesses, but nothing quite like this.
Back at home after being hospitalized for two weeks, it felt overwhelming to realize that I could no longer do the things I loved to do.

I Am Not to Blame!
by Sue - Wisconsin, USA
My sons were diagnosed with a rare bleeding disorder in 1993. I learned all I could about their care and what I needed to do to keep them safe. A few years later I heard the term "symptomatic carrier" and finding out what it meant made me realize that maybe that term applied to me. I started by being tested (at age 31) for the same disorder my sons had been diagnosed with. My levels were low but not low enough for medical intervention according to the hematologist.

Hope and Joy
Daeelle Nance, MD
Hemophilia Care Program
Purdue South Bend Center
There's a lighted balloon, floating peacefully, round and white and partially illuminated from below in the descending twilight. I watch it glowing and floating on its tether above the "Tacht" sales office on the river. At first I thought it was a reflection of the full moon, a trick of the window in the early darkness, as I gazed out across the water and the crowded shoreline of Lake Union, in Seattle. It's the very first of my research patient problems and discusses the major aspects of each patient situation, and make decisions with the attending physicians about what to do next to help people deal with and conquer disease.

Prayers In A Metal Box
Reverend Karen A. McCracken and husband Gary Lawrenceburg, Kentucky USA
For many of those working on the front lines of Emergency services, it likely doesn't register in their mind as a 911 call to sit and ponder what it's like to be the one strapped to a cot riding in a big metal box barreling down the road at 80 miles per hour. For a nurse, paramedic, and EMT, it's a routine part of the job. I was a paramedic and EMT, and I was in that metal box burning fluorescent every small task that was taking place around me in that metal box burning rubber down the interstate. I praise the Lord that the paramedic and EMT were in my place. I wanted them not sitting around worrying about what it would be like if they were in my place. I wanted them fully tuned in to their job. I needed them to be because I had no idea what was happening to me or why.

Living with a rare bleeding disorder
by Lori Hebron, Kentucky USA
I am a woman, a wife, a mother, and a student. I started my period at a very young age. I think I was 11. I was very petite for my age. My doctor put me on birth control pills by the age of 13. I bled during my pregnancy with her and I bled during my pregnancy with her and I bled during my pregnancy with her.

Leading the Way for My Family
by Elaine Grafion, Wisconsin USA
My three girls, my son, my sister and I all have Von Willebrand disease (vWD) Type 1. We didn't know there was any Von Willebrand disease in our family until I was 17. This was not a typical thing for me to be discovered, especially back then, but the dentist told me I probably had it. When I finally got a name for my disorder from his doctor and referred me to an Army it's not a typical thing for doctors to deal with. So I ended up receiving many treatments, many were the wrong ones.

Meet Niki and her Girls
by Niki - Macomb, Illinois
Isabelle was born on April 29th at 7:19 pm, she was perfect and healthy and wonderful. On Saturday May 1st we were due to go home and she had her heel prick done that morning about 5am to do the typical newborn screening. When we got ready to go at about 10 am her bandaid came off her heel but I didn't think anything about it because I assumed she was fine. When I got her dressed I noticed that she had bled on her blanket, not enough to be alarming, but enough so that we put on another bandaid morning at home. I look off the band aid and there was no more bleeding.

Meet Laura - CA
Over the course of the next two weeks, her umbilical cord bled much more than I remember. I called the Dr about it and mentioned it at our office visit on Monday May 10th. Dr. Lockard treated the umbilical stump with silver nitrate.

Journey to Awareness
by Laura - Hutsiford, WI
I guess I should have suspected something was not exactly right with the way my blood clotting. From the first period, at the age of 12, I suffered from heavy bleeding and had to stop that I had it. There was one time when I went with my cousin Shelby for a week and I got to be with a kid my age who also had a bleeding disorder like me. I couldn't wait to go back to see my friends.

Weaving My Own Life
by Laura - California, USA
I am 22 years old and I am learning to become more independent. My goals for becoming independent are being able to cook on my own, being able to get a job, and support myself. I want to be self-sufficient. I'd like to be able to self-infuse on my own with no help from someone else. I need to learn how to monitor my own business. I don't have to be told when it is time to self-infuse.

Living with a rare bleeding disorder
by Michelle Tempe, Arizona
I always knew that my dad had hemophilia, and that I was a carrier, but it wasn't until I was five years old that I was tested and found to have lower clotting factor IX levels as well. Of course, years ago I was told that I was a carrier, and I was told that if I was a carrier, I might have bleeding disorders. That was it. My test results were set aside, and I was told that I never had surgery I might have a long life, so that I was a carrier of given as a long life. However, I began when I started playing soccer.

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This unexpected Life
by Priyanka - Delhi, India
It's dark, very dark and you have so much of suffering. Holding the candle of hope and running through the darkness, is making you determined, to overcome the obstacles on your way to prosperity and peace.
The storms of hopelessness may make you feel lost, but the king of the universe, is there, up above the sky and will give you strength and courage.
You unquestionably accepted the destiny of life, but there lies an ocean of dreams, aspirations and compassion inside your heart.
Life is not a calm wave lapping the shore line and will not always provide rewarding opportunity. Lying in that opportunity in every adversity will bring joy and satisfaction to you.

Living Life
Heidi - Washington, USA
I grew up in the '70s and had what I would call an average life. My parents divorced and I by herself. I was a "good kid." I had lots of friends. Nothing traumatic happened in my childhood. I lived with lots of bumps and bruises, but I never had any pictures to prove it.

My Life with Von Willebrand Disease (vWD)
by Moline - Kenya
I was five years old, when I started nose bleeding frequently in a sequence or almost once in every week or after involving myself in activities like playing too much. People were saying that it was a natural problem or occurrence to some people and that it would heal up by itself as I grew up. I was even given herbal medication which did not help. I visited a few clinics where I was taught how to manage it: using very cold water; that is the normal first aid for nose bleeding and putting cotton wool soaked with liquid paraffin in my nose, which would reduce the frequency of occurrence. I was very eager to see the problem end since my parents could no longer afford the clinic visits with my mother earning only 3 dollars per day at that time plus taking care of other family needs, with us living in Mathare slums.

Delayed Diagnosis
by Laura - New York, USA
I was 46 years old when I was diagnosed with von Willebrand disease... by a pediatrician!
I went with my teenage son for his annual physical. During the appointment I asked the pediatrician if my son could be tested for allergies. The doctor asked me why I would want to have him tested. I had been getting a lot of nosebleeds and I thought maybe he was allergic to something in my house.
I was surprised when the doctor turned to me and started asking me about my medical history.

An Undiagnosed Symptomatic Carrier
by Michelle Tempe, Arizona
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Website: www.mygirlsblood.org
Send your story to: mygirlsblood@yahoo.com