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# PATIENT-LED AWARENESS RAISING ACTIVITIES as a TOOL in INCREASING INITIAL DIAGNOSIS

FOR PEOPLE with **BLEEDING DISORDERS** based on **FAMILY HISTORY** when **LABORATORY TESTS** were not **AVAILABLE**

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## Introduction

Diagnosing bleeding disorders in the Philippines continues to be a challenge because of lack of diagnostic facilities and lack of awareness among primary health care practitioners.

Case study presents efforts of a family whose youngest child manifested epistaxis (chronic and severe nosebleeds) since she was less than 1-month-old. Routine blood tests done in the Philippines showed all results to be within normal range. However, patient continued to have frequent epistaxis which at times occurred daily for weeks.

Despite family history of bleeding, including the death of patient's maternal grandmother due to excessive bleeding, none of the physicians consulted over seven years considered the patient as candidate for bleeding disorder. This caused agony to the patient and her parents for years. Patient was brought overseas and laboratory tests done in Hongkong showed she has von Willebrand Disease Type 2M.

## Objective

- Improve early diagnosis of bleeding disorders by empowering diagnosed patients and their families to do awareness raising activities within their network.

## Methods

- Powerpoint Presentations
- Personal Blog
- Face-to-face Meetings
- Group Presentations
- Media Relations/Media Interviews

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### Help sought for 1M Filipino hemophiliacs

By Dona Pazzibugan  
Philippine Daily Inquirer  
First Posted 23:01:00 10/13/2008

Filed Under: Diseases, Foreign Aid

MANILA, Philippines—Seven years ago at age 20, Angelo Cuevas altogether stopped going to school and shut himself from life in their house in Pateros.

He suffers from hemophilia, a rare but debilitating bleeding disorder usually among men that causes painful internal bleeding, severe joint damage, disability and even death when not treated.

Cuevas was diagnosed when he was two, "and since then life has been hard, financially hard."

Treatment consists of intravenous infusions of a medicine called antihemophilic clotting factor, to stop blood-clotting. It is also very expensive.

In Cuevas' case, the cost runs up to P15,000 a day since he needed to be infused with at least six vials of the life-saving factor each day. A vial costs P2,500 each.

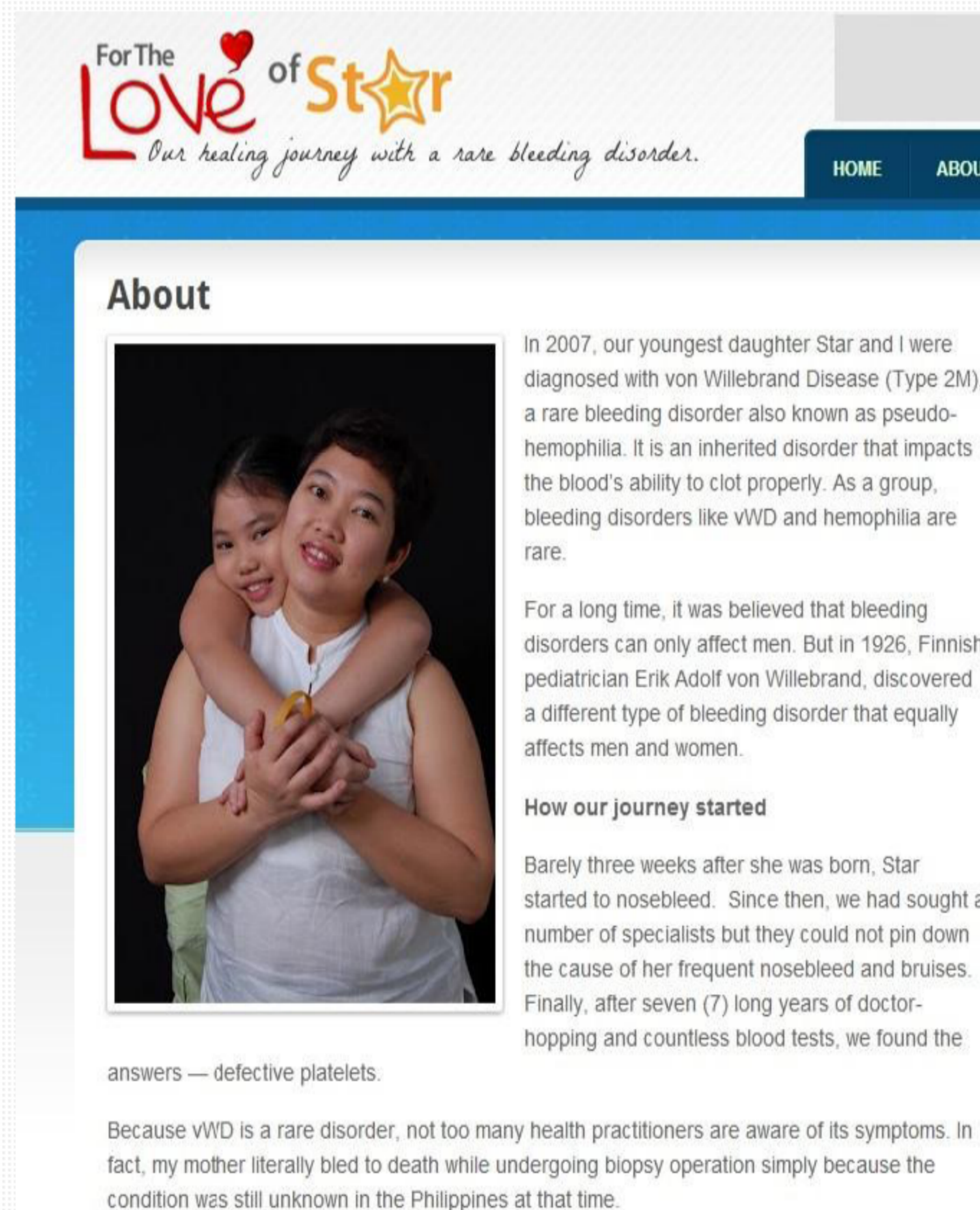
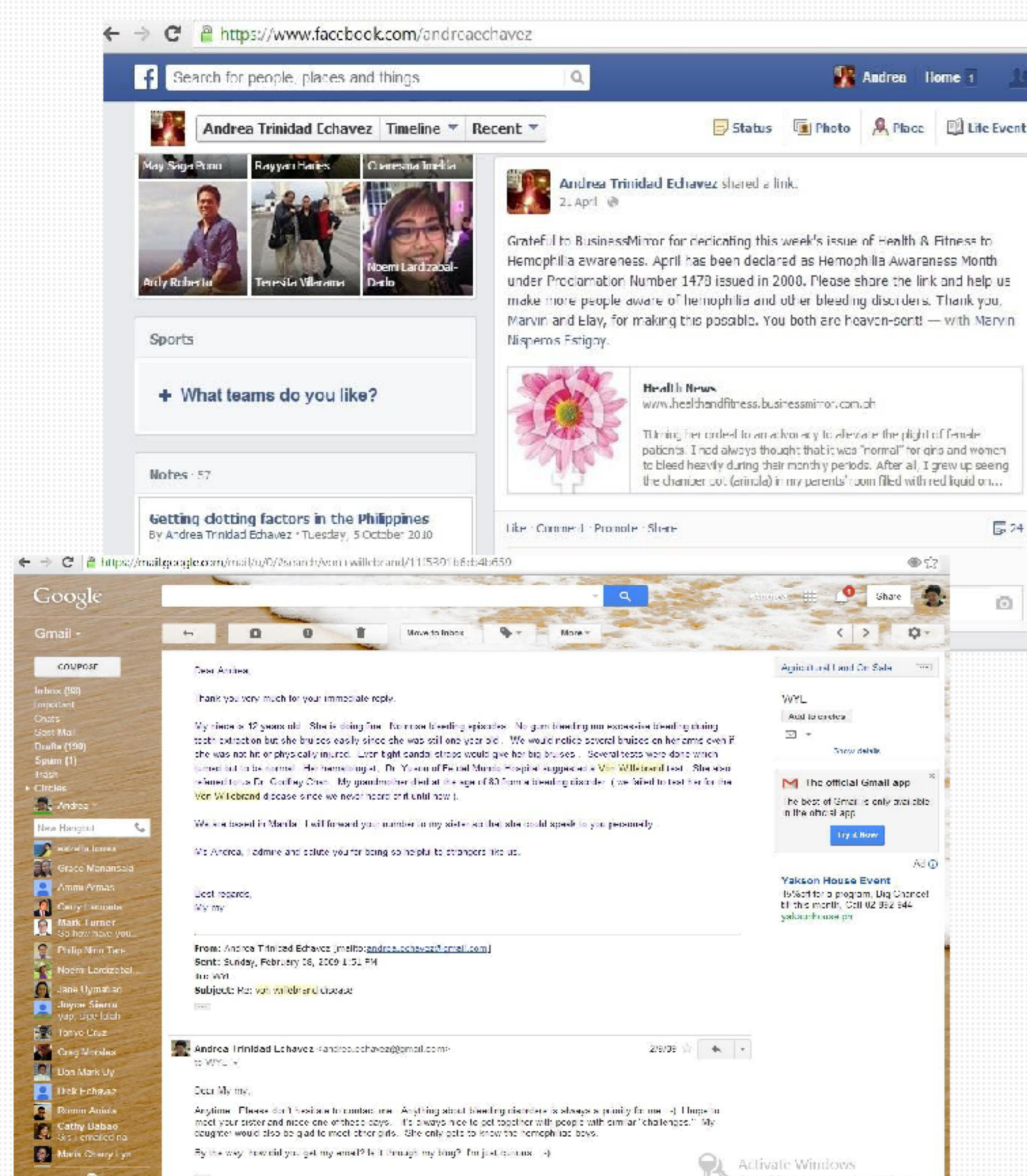
Just a few years younger than Cuevas, 21-year old Tommy Kelley in the United States has been diagnosed with hemophilia when he was a baby.

"If you look at my son today, you'll never know anything was wrong with him. He has a completely normal life because he has access to medicine," said Tommy's mother Laureen Kelley.

The difference in their quality of life is the availability and affordability of the antihemophilic clotting factor, one of the most expensive medicines in the world, according to Kelley.

Kelley founded Project SHARE eight years ago after she saw the condition of hemophilia victims in poor countries which she said "shocked" her.

"I can't imagine a country where the drug is not available. In the US we have so much medicine," said Kelley, who is visiting the country.



Above, the author's mother Sofia Lopez-Vito Hernandez, died of blood loss at age 51 while undergoing biopsy operation. She was undiagnosed. At left, the author blogs about her family's journey with von Willebrand Disease and their advocacy for the hemophilia community in the Philippines in [www.fortheloveofstar.com](http://www.fortheloveofstar.com).

## Results

Within a period of seven years, at least five other children were diagnosed with various types of bleeding disorders from among the medical practitioners who had interaction with the patient's family.

## Conclusion

The involvement of diagnosed patients and their families in informing primary health care practitioners and the general public on bleeding disorders through face-to-face meetings, groups meetings, and media interviews, increase the probability of new diagnosis and subsequent early intervention among pediatric patients.

