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# Guam's quest for improved hemophilia care

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## Introduction

Hemophilia and von Willebrand's Disease (VWD) inherited bleeding disorders in which the blood does not clot properly. These life-long chronic conditions can have physical complications, as well as significant emotional, social and financial consequences. While they cannot be cured, with proper diagnosis and treatment, people with these disorders can live a normal life, and have a normal life span. Both hemophilia<sup>1</sup> and VWD<sup>2</sup> are found throughout the world, in people of all racial and ethnic backgrounds.

Hemophilia affects mostly males, but some female family members may also have bleeding problems. In some cases, the disease appears in families with no history of it. Typical hemophilia bleeding is internal, affecting joints (primarily knees, ankles and elbows), and results in chronic joint swelling, pain, and crippling, if not properly treated. Central nervous system bleeds can be fatal. Hemophilia is rare: it occurs in 1 out of 5000 males<sup>1</sup>.

VWD affects males and females equally. It can be inherited from either parent. It usually causes less severe symptoms than hemophilia and can be difficult to diagnose. Typical signs and symptoms of VWD bleeding include easy bruising, frequent nosebleeds, prolonged menstrual periods, and prolonged bleeding following injury, surgery, dental work

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and childbirth. VWD is much more common than hemophilia — found in one out of every 100 persons<sup>3</sup>. But it is vastly under-recognized by health care professionals and the public.

On Guam, a total of 64 cases (35 hemophilia, 14 hemophilia carriers and 15 VWD) have been identified and an additional 23 cases are undergoing diagnostic evaluation.

## Isolation of Guam hemophilia patients and families

Before 1996, there were no programs or services that addressed the health and social needs of Guam's hemophilia community. The Department of Public Health and Social Services (DPH&SS) is an agency of the Government of Guam, and is responsible for overseeing the health and well being of the people of Guam. Medical Social Services is a section within the DPH&SS and is comprised of eight social workers who assist individuals and families with their health care and related emotional needs. In the 1990's, the MSS social workers became increasingly aware of a growing number of families with one of more children suffering from bleeding disorders. Most island health care providers, consumers and their families had minimal knowledge about the diagnosis and treatment hemophilia and VWD. And all health insurance companies on Guam denied coverage for hemophilia medications, which are made from blood and blood products. Almost all care was on an emergency basis; serious cases were evacuated to Hawaii for treatment, a flight of more than seven hours.

## The spark for program development

In 1995 one young Guamanian boy with a hemophilia related intracranial hemorrhage was flown to Honolulu to receive emergency treatment at Tripler Army Medical Center as part of Tripler's Pacific Outreach program. Tripler alerted the Hemophilia Foundation of Hawaii, which provided education and support to the family. As the Hawaii Hemophilia Foundation's funding limited their ability to provide services into the U.S. affiliated Pacific, they sought the help of the regional office of the U.S. Federal Hemophilia Program/Region IX. The Region IX Hemophilia Program administers grants from the U.S. Maternal and Child Health Bureau and

**Most island health care providers, consumers and their families had minimal knowledge about the diagnosis and treatment hemophilia and VWD.**

**Table 1. Key consumer advocacy and support systems developed**

*Hemophilia and Bleeding Disorders Foundation of Guam (HFOG) -- not for profit consumer information, support and advocacy agency. Provides:*

1. Medic-Alert Bracelets
2. Social opportunities to develop family support networks
3. Fundraising events
4. Annual Public Awareness Month
5. Public Awareness through booth at Chamorro Village
6. Legislative Advocacy -- obtained insurance plan coverage of blood/blood products for employees of Government of Guam
7. Family Education/Recreation Camp, "Camp Hafa Adai"

*Hemophilia Youth Program to Educate (HYPE) -- Youth subcommittee of HFOG*

1. Educational/recreation/support outings for affected youth and siblings
2. Website
3. Video created and presented at public school

Centers for Disease Control and Prevention to improve the health status of persons with hemophilia and VWD. These grants support a regional network of over 130 comprehensive Hemophilia Diagnostic and Treatment Centers (HTC) specialty centers. HTCs uniquely use multidisciplinary clinician teams to provide comprehensive diagnostic and treatment services and to reduce hemophilia complications. The core team members are hematologist, nurse coordinator, social worker and physical therapist.

The Region IX Hemophilia Program Coordinator immediately set up a task force to conduct a baseline survey to determine extent of hemophilia in the U.S. Pacific. 100 (40%) of the 250 physicians contacted responded. The survey was completed in 1996. It revealed that 27 (11%) respondents (primarily from Guam and Saipan) reported having patients with a diagnosed bleeding disorder. An additional 37 clinicians (chiefly from Guam, the Island of Yap and Belau), had patients with symptoms suggestive of an inherited bleeding disorder. Three-quarters were interested in additional information.

The Region IX Coordinator contacted the MSS Supervisor and together they began planning to improve hemophilia care in Guam. The plan had two main goals, which needed simultaneous attention. The first was to educate affected consumers about their disorder and how to advocate for their own behalf. The second was to identify and educate local team of clinicians who were interested in developing hemophilia expertise. The MSS Supervisor agreed to be the lead Guam contact, coordinating the progress of both goals.

### **Educating and organizing consumers and clinicians**

Increasing local expertise through regional mentoring is a core Region IX approach. *See Table 1 for key consumer advocacy and support systems developed.* One key strategy was for Region IX to sponsor families, and MSS staff, to attend the hemophilia family camp organized by the

Hemophilia Foundation of Hawaii. Between 1996 - 2000, over 20 affected Guam children and family members attended the Hawaii fun and educational camp. In August 1996, Region IX sponsored, the Executive Director and Founder of the Nevada Hemophilia Foundation to visit Guam to conduct an in-depth educational and training symposium for the medical community, and to also educate affected persons about their disorder. She also assisted patients with bleeding disorders, their families and interested citizens in establishing a private, non-profit organization, which has come to be known as the Hemophilia/Bleeding Disorders Foundation of Guam or HFOG.

### **HFOG board and activities**

The Board of Directors for HFOG consists of 17 health professionals and affected family members who volunteer their time to improve the quality of life of affected persons through education, peer support, advocacy and referral. The board meets regularly to address issues that effect the Hemophilia community. They have held fundraising activities, primarily a walk-a-thon, which raised enough money to allow HFOG to purchase "Medic-Alert" bracelets for identified consumers.

For the past five years, Guam has designated March as Hemophilia Month. The "kick off" traditionally starts with an official proclamation by the Governor declaring Hemophilia Month. A fiesta and beach party for the patients, families, medical providers and the public soon follows. During the month, a public awareness campaign is undertaken via radio interviews and newsprint media. Through these activities, HFOG also fosters family support networks.

A significant milestone occurred in 1998 when HFOG successfully lobbied the Legislature to pass a law requiring insurance coverage for blood and blood products for employees of the Government of Guam. This allowed fifteen of our affected families to obtain insurance coverage for their hemophilia medication (called factor concentrate) for the

**Table 2 Key clinical systems developed**

Guam Comprehensive Hemophilia Care Program (GCHCP) -- multidisciplinary clinical team coordinated by the Medical Social Services Section of the Guam Department of Public Health and Social Services. Core team members -- program coordinator, pediatrician, nurse coordinator, social worker, physical therapist and dentist receive extensive ongoing training in hemophilia clinical diagnosis and treatment and public health program management.

GCHCP provides:

1. Patient Registry
2. Monthly clinics for diagnosis and treatment
3. Education and home visits to teach and reinforce medically supervised home therapy
4. Linkage to Guam Public School system
5. Referral network with Public Health outstation clinics
6. Patient data aggregated annually for the national hemophilia data set
7. Research: study site for the Centers for Disease Control and Prevention nationwide prospective surveillance of hemophilia complications
8. Technical assistance to Guam Pharmacists, Medicaid and Medically Indigent Program on cost effective purchasing of hemophilia medication
9. Staff of Family Education/Recreation Camp, "Camp Hafa Adai"
10. Tertiary consultation linkage with Kapi'olani Medical Center, Hawaii
11. Consultation to Commonwealth of Northern Mariana Islands

first time. Currently there is an aggressive effort to extend this benefit into the health insurance policies of private sector employees.

Most recently, received a grant from the National Hemophilia Foundation to sponsor the very first Hemophilia Summer Camp on Guam. This was truly remarkable considering that HFOG is only 5 years old. Camp Hafa Adai, as it was called, was successfully held in August 2001. Camp Hafa Adai offered educational and recreational camping experiences for children and adults with bleeding disorders. Fifty-six consumers and some family members participated.

### Youth group

HFOG's newest program is "HYPE" (Hemophilia Youth Program to Educate). HYPE is comprised of youth up to 25 years old whose purpose is to educate the youth of Guam regarding the care of patients with Hemophilia and von Willebrand's Disease. Currently there are 30 active youth members and two adult advisers. They have elected officers and developed a constitution and by-laws. The group meets on a quarterly basis in location chosen by the members. Their meetings are usually fun-filled combined with educational lectures on reducing hemophilia complications such as "learning how to splint," "decision-making", etc. To date, their greatest accomplishment is the creation of a website: [hype.freeshell.org](http://hype.freeshell.org), which is regularly updated by the members themselves.

### Hemophilia treatment team

The second major goal — to identify and develop local clinician expertise in hemophilia and VWD diagnosis and management — has also met with solid success. *See Table 2 for key clinical systems developed.* It is vital for Guam to

have an HTC. Recent CDC data documents that males who obtain their hemophilia care at a federally recognized HTC have a 60% reduced risk of mortality<sup>4</sup> and 50% reduced risk of bleeding related hospitalization<sup>5</sup> as compared to males who receive their hemophilia care outside these HTCs. In 1998, the Guam Comprehensive Hemophilia Care Program (GCHCP) was created, coordinated by MSS. Guam's version of an HTC is comprised of a team of pediatricians, hematologists, nurses, physical therapists, dentists and social workers from different organizations and agencies in the public and private sector. These team members receive ongoing training through two methods. Off-island Region IX clinician leaders are sponsored to visit Guam to conduct clinical consultations with the GCHCP and patients' primary care providers, to lecture at hospital grand rounds, and give presentations to the Guam medical professional societies. Alternatively, Region IX sponsors GCHCP clinicians to attend mainland clinical education seminars.

GCHCP core team members meet to discuss the clinical health and medical management issues of over 60 bleeding disorder consumers. In monthly clinics, affected patients are educated about their disorder, how to recognize internal bleeding, how to treat routine bleeds at home (with medical supervision) and how to prevent complications. These efforts result in cost savings to the Government of Guam: emergency transports to Hawaii have been reduced to zero. Hospital admissions for routine treatment have also been eliminated since nearly all patients now know how to self-administer their hemophilia medication. Most importantly, a dependable and consistent supplier of factor products has been identified. Telehealth is now being explored to strengthen our linkages with specialists at HTCs in Hawaii, and, ultimately, the mainland.

Because GCHCP is part of the U.S. of HTC's, eligible patients are able to voluntarily participate in a CDC sponsored nationwide prospective surveillance system, which monitors joint damage and blood borne viruses. Nearly 40 Guam patients have agreed to participate in this annual study. GCHCP clinicians have received training in the ethics, rules and regulations surrounding human subjects research.

## News of Guam's hemophilia programs gains international attention

Articles on the plight of hemophiliacs on Guam and the creation of the GCHCP were published in the newsletter of the World Federation of Hemophilia (WFH), an international non-governmental agency representing over 95 member nations. GCHCP is listed as a federally recognized HTC on the websites of the National Hemophilia Foundation (NHF) and WFH.

Furthermore, the GCHCP is now strong enough in its knowledge base to share their with the neighboring Commonwealth of the Northern Marianas Islands (Saipan) by conducting educational presentations to various healthcare providers and affected families. Two Saipan families joined Camp Hafa Adai.

In 2001, the Taiwan Hemophilia Association chose Guam as their site to have a weeklong summer camp. Why Guam? Because of the existence of an organized hemophilia program on Guam, the group of seventy-seven Taiwanese hemophilia children, family members, medical staff, escorts, media representatives, tourism officials and interpreters felt secure that medical emergencies would be appropriately handled. Coincidentally, the Taiwan group visited during the weekend that Camp Hafa Adai was held. As a sign of goodwill and hospitality, the Taiwan colleagues were invited to an appreciation luncheon during the last day of camp.

## Conclusion

The past five years has witnessed tremendous improvements in the health status of Guam's hemophilia and VWD population. Affected persons and their family members know what their disorders are and how to recognize and treat routine bleeds. They know which bleeds are more life threatening and require immediate calls to the well-trained core team of GCHCP clinicians. There has been a reduction in days lost from work and school due to bleeding episodes. Government employees with these disorders have health insurance plans, which now cover their medicines. Patients with suspected bleeding disorders are rapidly referred to the GCHCP. These patients have a support network to meet similarly affected families so they are not isolated. Patients participate in national research, which will improve our understanding of hemophilia complications and ultimately

lead to better prevention interventions. All of these positive changes allow clinicians and affected persons to work together to prevent and reduce hemophilia complications.

Yet, despite of the dedication and commitment of the people behind the successes of the Hemophilia programs on Guam, their tasks are far from being complete. The programs are faced with limited resources compounded with a faltering economy. Treatment for Hepatitis C is complicated and costly. The lack of sub-specialties, such as Hepatologists, Orthopedists and Geneticists on Guam are barriers to providing comprehensive medical care. Hemophilia medicine is very expensive and there is currently an international shortage. Although we have come far, much work remains to sustain and strengthen our programs. The Guam hemophilia community must now stand together and push just a little bit harder to achieve the goals that they have set for themselves. Nevertheless, despite our geographic isolation, and relative dearth of resources, being part of a regional program has made a tremendous difference in serving a population with rare, chronic, inherited disorders. Indeed, this model has much to offer in the larger public health arena.

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