Capacity Building for Rare Bleeding Disorders in the Remote Commonwealth of the Northern Mariana Islands

Tiffany F. Lin, MD, Pam Carhill, MPT, James N. Huang, MD, and Judith R. Baker, DPH, MHSA

The Commonwealth of the Northern Mariana Islands (CNMI) is a medically under-resourced US commonwealth territory located in the Pacific Ocean that is home to 53,883 residents. CNMI is federally designated as a medically underserved area and a health professional shortage area in primary, dental, and mental health care. The CNMI consists of 13 islands of 183 square miles, only 3 of which are significantly populated. The northernmost island lies more than 500 miles from its southernmost island. CNMI’s geographic isolation and lack of medical resources complicates the development of patient registries and the optimal treatment of rare disorders.

For orphan diseases (those that affect fewer than 200,000 people in any particular country), a critical patient mass and links to regional or global networks are vital for developing local expertise to facilitate management. CNMI is located more than a 12-hour flight away from the US mainland’s west coast. Isolation is exacerbated by the high cost of round-trip airfare to CNMI from the continental US, which is typically more than $2000.

Bleeding disorders can be life threatening and disabling, so early identification and treatment is essential. Regional efforts to establish hemophilia care in the US Pacific in the 1990s first focused on Guam and then expanded to CNMI by engaging a local physical therapist. However, lack of community awareness and provider participation stymied CNMI’s hemophilia care implementation. Care establishment regained traction with the 2014 arrival of a pediatric hematology and oncology fellow from the University of California, San Francisco.

We developed a strategy to provide education, raise awareness, and lay the groundwork for sustainable care of patients with bleeding disorders in CNMI.

METHODS

In this remote locale, the first task was to identify and confirm specific diagnoses. The physician and physical therapist updated the census of bleeding disorder patients. They identified new patients through a fall 2014 community outreach event. This patient census was vital to gaining recognition from the local department of public health.

The Western States/Region IX Hemophilia Network leadership then facilitated partnerships between the physician, department of public health, and provider participation, which helped CNMI’s hemophilia care implementation. The education series proved feasible, efficient, and effective in increasing knowledge and reducing patient and professional isolation, serving as a model for improving capacity for orphan diseases (those that affect fewer than 200,000 people in any particular country) in underresourced areas. (Am J Public Health. 2016;106:658–661. doi:10.2105/AJPH.2016.303093)
private clinic (Marianas Health), industry (Biogen-Idec), and a regional hemophilia treatment center (the Los Angeles Orthopedic Institute for Children).

The Western States/Region IX Hemophilia Network is a Health Resources and Services Administration grant–supported consortium of 14 comprehensive hemophilia diagnostic and treatment centers that provide diagnosis, treatment, prevention, education, outreach, research, surveillance, and low-cost outpatient pharmacy services; it aims to improve care for all residents with hemophilia and related genetic bleeding and clotting disorders in California, Guam, Hawaii, Nevada, and the US affiliated Pacific Jurisdictions. These partnerships augmented locally available resources, and with shared goals, they aligned to promote health and improve care for those with bleeding disorders.

Improved awareness in the community of patients with rare disorders is key to optimal management. We created a weeklong bleeding disorders educational series in December 2014—rather than a single-day, single-discipline event—to build synergies across professions and catalyze learning. We invited all health care professionals in the community. We tailored the agenda content to each audience on the basis of its scope of practice, with each day offering approximately 4 hours of education plus networking (Table 1).

We used consistent processes for registration and attendance certification for the conference. Lectures by the physician and physical therapy experts covered essential medical, musculoskeletal, and supportive care practices. Coaches and health educators learned about signs of the disease to facilitate identification of patients, and providers were educated about diagnostics and treatment. Meals and exercise breaks were incorporated to improve networking and health promotion. We used pre- and posttest evaluations to quantitatively measure knowledge gains.

The evaluations consisted of true or false and multiple-choice questions covering bleeding disorder topics, including recognition of signs of disease, how patients can be managed, and potential complications of the diseases. Furthermore, the postactivity evaluations qualitatively assessed participants’ learning experience and future education needs. Each day concluded with sharing available resources. Nurses and social workers received continuing education credits. For patients and families to gain support and education, the series culminated in a weekend camp staffed by many professionals who had attended the weekday events.

### RESULTS

Before the conference, we identified 19 patients with bleeding disorders or with carrier status with hemophilia A and B or von Willebrand’s types 2A, 2B, or 2N. Three were newly diagnosed with bleeding disorders, and 3 were newly identified as carriers.

The total cost for the weeklong event was $48,409. Costs covered facilities fees, educational handouts, working meals, patient lodging and travel, and personnel and speakers. With

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<thead>
<tr>
<th>Day</th>
<th>Target Audience</th>
<th>Educational Goals</th>
<th>Participants, No.</th>
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<tbody>
<tr>
<td>1</td>
<td>Athletic coaches, health education primary and secondary school teachers, and community advocates</td>
<td>Discuss the basics of bleeding disorders and their prevalence. Increase awareness of the impact of the disease in the community.</td>
<td>60</td>
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<tr>
<td>2</td>
<td>Social workers, nurses, hygienists, physical therapists, and home health workers</td>
<td>Understand bleeding disorders’ signs, symptoms, and appropriate treatment. Stimulate frontline clinicians to better understand the physical and psychosocial challenges of bleeding disorders.</td>
<td>58</td>
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<tr>
<td>3</td>
<td>Clinical team interested in providing care for patients with bleeding disorders</td>
<td>Understand patient census and gradations of their diagnoses. Build knowledge and regional and national hemophilia resources and expertise.</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>Medical providers and dentists</td>
<td>Learn correct diagnostic tools and locally available treatments. Understand differential diagnoses of rare bleeding disorder treatment difficulties.</td>
<td>24</td>
</tr>
<tr>
<td>5</td>
<td>Bleeding disorder patients and their families</td>
<td>Improve understanding of their disease. Increase empowerment to advocate health. Experience caregiver support for patient challenges.</td>
<td>65</td>
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212 participants, the average cost was $228 per attendee.

A total of 142 clinicians, coaches, and teachers attended the educational conference before the family camp, representing the majority of professionals on CNMI in each target audience (e.g., all CNMI dentists attended; Table 1; agendas are available in a supplement to the online version of this article at http://www.ajph.org as Supplement 1). Every patient attended the family camp.

Attendees completed 135 pre- and 141 posttests (representing 95% and 99% of the professionals attending the conference series, respectively). Pre- and posttests documented improvements in all learning objectives (evaluative tools available in a supplement to the online version of this article at http://www.ajph.org). The most profound gain was in basic knowledge on how to prevent bleeding: correct responses rose from 39.2% to 93.6%; more than 90.0% reported knowledge gains in all domains, and 90.0% to 100.0% from different disciplines reported learning something new. All patients and families completed a modified version of the National Hemophilia Treatment Centers Patient Needs Assessment,12 providing a baseline and identifying priority information and service needs. Qualitative feedback from health care professionals and patients further confirmed the series’ educational value.

**DISCUSSION**

A weeklong conference series about a rare disorder in a geographically remote area that is medically underserved proved to be a feasible, efficient, and effective educational method to increase patient and professional knowledge and reduce isolation. Capacity building in the CNMI started with identification of the bleeding disorder population. This education paradigm helped build a foundation for patient identification and sustainable care. Connection to regional infrastructure provided critical connections with expert speakers, galvanized local health department support, ensured continuing education units, and guided program planning and evaluation.

Advancing local provider education should foster patient care delivery in line with current recommendations.13 Of note, since the education intervention, a child aged 6 years with severe hemophilia began treatment to prevent long-term complications of the undertreated disease,14 both a teenage and a preteen patient started physical activity in a safe manner that was previously thought prohibitive,15–17 numerous dental procedures were performed safely,18 and a patient who was receiving an ineffective medication switched to the correct type.

Conducting the educational conference in a single-week format maximized efficiency in both monetary terms (e.g., stretching a single airfare for a mainland speaker to present work at 5 distinct events) and human resources (e.g., newly educated coaches and providers volunteering as staff at the patient and family camp). Furthermore, the weeklong design of the intervention maximized local attention to this rare disease. This conference series catalyzed ongoing local continuing education and networking, facilitated rapid implementation of future diagnosis and treatment developments in the CNMI, and provided proof of concept for frontier area public health initiatives for rare disorders.

Clinicians in underresourced areas should access regional and global networks for local capacity-building guidance. Underserved frontier areas typically employ a small number of providers who stretch limited resources to serve patients. These
providers are eager to participate in educational opportunities, which offer rare professional networking opportunities. Implementing a weeklong tailored educational series gives frontier providers, supportive care staff, community members, and families a learning structure that honors time and resource scarcity, thus eliminating the need for costly and time-prohibitive travel. Through this example we hope to inspire frontier providers to access their regional and national resources to improve care for their orphan disease populations.

CONTRIBUTORS
T.F. Lin was the primary author of this article. T.F. Lin and P. Carhill conceptualized and carried out the project. T.F. Lin and J.R. Baker wrote the article. J.N. Huang assisted in data analysis and interpretation. J.R. Baker provided technical assistance in project planning, funding, and evaluation and assisted in data analysis and interpretation. All authors reviewed and edited the article and approved the final version.

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HUMAN PARTICIPANT PROTECTION
The University of California, San Francisco institutional review board approved this study (IRB 14-1440).

REFERENCES