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

The US Pacific Commonwealth of the Northern Mariana Islands is home to an underserved hemophilia population. We developed a strategy in 2014 to build sustainable island-wide medical, patient and family, and community support for this rare disease. Collaboration with regional bleeding disorder leadership galvanized a weeklong conference series. More than 200 participants attended discipline-specific seminars; pre–post test evaluations documented educational benefits. This time-concentrated island-wide education intervention promoted the rapid identification of new cases and stimulated sustainable bleeding disorder care development. 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. Published online ahead of print February 18, 2016; e1–e4. doi:10.2105/AJPH.2016.303093)

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 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.

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public health, a 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.11 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,

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<th>TABLE 1—Audiences, Educational Goals, and Participants: US Pacific Commonwealth of the Northern Mariana Islands Bleeding Disorders Education Series, 2014</th>
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and personnel and speakers. With 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 teenager 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 well-planned 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.

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HUMAN PARTICIPANT PROTECTION

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

REFERENCES


