A Noble Partnership: Supporting Sustainable Pediatric Cancer Care in Uganda

IN THE UNITED STATES, less than one in five children diagnosed with cancer will die. In Uganda, only one in five children diagnosed with cancer will survive. The percentage of children with cancer who are actually diagnosed is unknown because access to care remains limited.

“The prognosis for cancer should not be based on where you live,” Howard Weinstein, MD, said.

“We honestly do not know how much cancer we have in Southwest Uganda because we believe that most children die in their community before they are diagnosed,” Barnabas Atwiine, MB ChB, MMed., said. “We believe that we see a small fraction of the children with cancer.”

Dr. Atwiine, who recently completed the East Africa Pediatric Hematology-Oncology Fellowship at the Ugandan Cancer Institute in the capital city of Kampala, leads the pediatric oncology program at Mbarara Regional Referral Hospital (MRRH), a partner of the Mass General Center for Global Health. He is one of 17 Pediatric Oncologists in the country of over 44 million, and the only one practicing in the Southwest Region.

Dr. Atwiine is hopeful that the success Uganda has seen in HIV outcomes can be replicated in childhood cancer given the proper resources. Mass General is working with Dr. Atwiine and MRRH to achieve this goal. Dr. Weinstein, the Mass General for Children Chief of Hematology-Oncology for over 20 years, has been instrumental in the growth of the program in Mbarara over the past four years, making multiple annual visits to provide guidance and training.

At the time of his first visit in 2015, MRRH was in the early stages of developing the pediatric oncology program. Children with cancer were treated in the general pediatric ward, often by necessity sharing space with patients with infectious diseases.

“Our initial shared goal was to try to create a better environment, a clinic and a ward that would really be separate from the general ward,” Dr. Weinstein said.

Around this time, Wellesley, Massachusetts teenager James Mooney visited MRRH with (Continued on the back page)

Advocating for Victims of Gender-Based Violence

ANNEKATHRYN GOODMAN, MD, MPH, is dedicated to fighting gender-based violence.

Gender-based violence (GBV) against women is a global pandemic as more than one billion women alive today are, or will be, victims. GBV is more than violence directed against a person because of their gender. GBV can be physical, sexual, psychological or economic, and often derives from power inequalities between the instigator and the victim.

Dr. Goodman is particularly interested in GBV following disasters, and recently held a city-wide journal club focused on articles related to this topic. “Gender-based violence exists regardless, but when a disaster hits the rates of it go up extraordinarily,” she said. One recent example is in Mozambique, where the UN is investigating reports alleging that community leaders forced survivors of Cyclone Idai to exchange sex for food.

Participants in the journal club included urologists, gynecologists, disaster responses professionals and other physicians involved in human rights advocacy work. “Everyone there could talk about ways (Continued on the back page)
Team Deploys to Support Recovery Efforts in Mozambique

**MASSACHUSETTS GENERAL HOSPITAL**
Center for Global Health (CGH) Office of Global Disaster Response (GDR) deployed a six-person team on May 8 to provide a professional response in support of residents affected by Cyclone Kenneth in Cabo Delgado Province, Mozambique.

The four teams took turns staffing the field hospital, as well as their own shelters for the following night.

Field hospital, as well as their own shelters for the following night.

**Global Disaster Response Trains Future Humanitarian Responders**

**THE MASSGENERAL** Center for Global Health Office of Global Disaster Response (GDR) held the Missioncraft 2019: Disaster Response Leadership in Austere Environments workshop from April 24 through the 27. The annual humanitarian responder course was redesigned for 2019, adding a field-based training element to provide more authentic preparations.

The Missioncraft 2019 classroom sessions were taught by course director Hilarie Cranmer, MD, MPH, her GDR team and Emilie Calvello Hynes, MD, MPH from the University of Colorado Department of Emergency Medicine. The roughly 25 participants from various international organizations engaged in discussions ranging from epidemiology to project management to basic field security.

“It’s really important to understand the basic principles and do some interaction and discussion regarding some of the tool sets you will need in the field,” Dr. Cranmer said. “For example, you need to see what a rapid health assessment is supposed to be before you actually have to be in the back of a car filling one out at 11 o’clock at night.”

On Friday morning Missioncraft participants dressed for the elements and traveled 20 miles north to the Harold Parker State Forest in Andover to participate in a disaster simulation held in conjunction with The Harvard Humanitarian Initiative. They were split into four teams that were responsible for setting up and running the simulation field hospital, as well as their own shelters for the following night.

The four teams took turns staffing the field hospital and taking part in different practical field trainings including environmental health, clinical medicine and media preparedness. Unseasonably chilly weather and scattered thunderstorms provided authentic challenges often found during humanitarian deployments.

“There’s nothing like shivering in a tent in the forest that really helps you bond with your teammates but also realize that you’re vulnerable and that you need to practice self-care while you are trying to deliver care for others,” Dr. Cranmer said.
Physical Therapy in Haiti: Paying it Forward

LARRY RONAN, MD, poetically described his mentor, Thomas S. Durant, MD, as a “very large bonfire” who would impact those he encountered with “life-changing sparks”. Almost 20 years after his passing, Dr. Durant’s legacy continues to have a positive impact.

Rachel Lampros, PT, DPT, a physical therapist with the Sports Medicine Center in the Mass General Department of Orthopedics, recently made her fifth volunteer trip to Haiti since 2015. Working as the Massachusetts Chapter Director of the nonprofit STAND, whose mission is to establish permanent access to orthopedic rehabilitative services in Haiti through direct patient care and clinical training of its citizens, she is committed to helping the Haitian people the right way.

“We do a lot of community outreach and education and we employ Haitian medical providers,” Dr. Lampros said. “We’ve been really focused to make sure this is sustainable and that we’re not creating a clinic that is reliant on this third party, but making sure that they have the skills to carry on and be completely autonomous.”

Founded in 2015, STAND operates a physical therapy clinic in Port-au-Paix, a city on Haiti’s northwest coast. Volunteer therapists from around the world open the clinic every couple of months and treat local citizens free of charge. Each time the clinic is open hundreds of patients receive free treatment ranging from acute pain management to the building of new prosthetics.

Dr. Lampros discovered the conviction to commit to this project long term shortly after returning from her first trip and evaluating what she had seen. “I remember talking to my mom about it and being like ‘that was so hard but I’m so fortunate to have these things I don’t worry about day in and day out. How can I pay this forward in some way?’”

While researching how to become more involved in Haiti, Dr. Lampros discovered the Thomas S. Durant Fellowship for Refugee Medicine, a fund that honors the late physicians’ “spirit of dedication and service through sponsoring health care professionals to serve refugee populations and victims of complex humanitarian disasters”. The Durant Fellowship has funded her three most recent trips.

Dr. Ronan is the director of the Thomas S. Durant, MD Fellowship for Refugee Medicine. “It is the legacy of Dr. Tom Durant to be present among the world’s poorest and most in need to bear witness and to provide what help we can, wherever and whenever we can,” he said. “Dr. Lampros follows in this tradition and we are proud to sponsor her work.”

Dr. Lampros credits her work with STAND for reminding her about the importance of the human connection in healthcare. “When you can connect with someone from a different culture in a way that may change their quality of life, such as providing for their family, it makes you feel like you’re making a meaningful difference,” she said.
— Supporting Sustainable Pediatric Cancer Care in Uganda

(Continued from the front page)

his parents who had supported projects at the Ugandan hospital through the Mass General Center for Global Health. James was so moved by the visit that he started the 5K Uganda Color Run for Cancer, an annual fundraiser that has "changed the whole face of pediatric cancer at this institution," according to Dr. Atwiine.

Now in its fifth year, the color run has raised thousands of dollars which have been used to hire nurses, build a beautiful new pediatric oncology ward and purchase medication.

"The color run is really a very creative way to bring awareness to the community about pediatric cancer," Dr. Weinstein said of his Ugandan colleague. "It's become an annual event that people are looking forward to and I think it's really just the beginning."

Dr. Atwiine was a pediatrician at MRRH who had always been interested in hematology and oncology. When the Uganda Cancer Institute created the Pediatric Hematology-Oncology Fellowship Program in 2016, he applied and was accepted. Upon completion, Dr. Atwiine returned to MRRH to run the pediatric oncology program.

"Dr. Barnabas has been a real leader in bringing together a team that can care for children with cancer," Dr. Weinstein said of his Ugandan colleague. "He's a very skilled, caring and compassionate physician and he's just creating a wonderful environment to really help these kids."

"Each day we learn something new," Imelda Busingye, RN, an MRRH pediatric oncology nurse says of working with Dr. Atwiine. "During the ward rounds he has taken an extra effort when seeing patients to teach us."

Busingye also credits the MGH Global Nursing Fellowship, which has sent MGH nurses to MRRH to work with their Ugandan counterparts, with helping her feel comfortable working in the pediatric oncology unit. "It's been a great experience working with the MGH nursing fellows," Busingye said.

Dr. Weinstein and other Mass General colleagues provide frequent support for their Ugandan colleagues both during visits to Uganda and remotely. Tumor boards and biweekly video conference calls between the teams allow for discussion and advising on issues from new cases to operational needs.

"This partnership is really enriching to MGH and together we believe that we are making a real difference in the lives of children and their families," said Louise Ivers, MD, MPH, DTM&H, Executive Director of the Center for Global Health, the entity at MGH that oversees the partnership.

Despite having the key elements of a successful department in place, new support is critical to sustain and progress. "Philanthropy remains a real key as far as making any headway going forward," Dr. Weinstein said.

"For me the greatest tragedy of cancer is children who die without anyone suspecting that they have cancer," Dr. Atwiine says. "The whole aim of this unit is to give every child a chance. A chance at diagnosis, a chance at treatment and a chance at a cure."

— Advocating for GBV Victims

(Continued from the front page)

in which GBV has presented itself in their work, and this journal club created space to tell these stories and think about possible ways forward; Kristen Giambusso, journal club attendee and Deputy Director of Baseline Operations at the MGH Office of Global Disaster Response, said.

As a member of the national Trauma and Critical Care Team and fulltime practicing Gynecologic Oncologist at MGH, Dr. Goodman is uniquely qualified to study this issue. She has deployed to numerous international disaster sites in her 25-year career.

"The thing that really interests me and gets back to this sort of meta level of why does this world do this? Is the framework of culture, how society is set up and the thought that what happens after a disaster merely uncovering what's there all the time?" Dr. Goodman asks. (We're) not dealing with the fact that gender-based violence is allowed in society, that it's unpunished, that it's expected almost in society."

Still in the early stages of convening interested professionals, Dr. Goodman is figuring out how their work can best address GBV. "My hope is to be a place where people can connect and have information exchanged and to find the tools that they need wherever they are in the world," she said.

In the meantime, Dr. Goodman is partnering with fellow MGH Associates in Global Health Adeline Boatin, MD, MPH, and Thomas Randall, MD, to produce a newsletter. ‘Global OB/GYN News: From Academics to Advocacy and Action’ is a monthly publication that focuses on newsworthy women’s health issues.

"The global health community has a responsibility to make every effort to address this issue," Louise Ivers, MD, MPH, DTM&H, Executive Director of the MGH Center for Global Health, said. "Dr. Goodman is a passionate advocate and I am proud to stand with her in the fight against gender-based violence."