

UMSAEP 2014 report on activities of the UM-UWC Linkage Program November 4-17, 2014

January 20, 2015

Professor Rodney Uphoff, Director of the University of Missouri South Africa Education Program
Professor Ramesh Bharuthram, Deputy Vice Chancellor (Academic) at University of Western Cape

Dear Professors Uphoff and Bharuthram:

As I submit this report, I would like to thank you again for the opportunity to participate in the UMSAEP program in 2014. The exchange of ideas and progress in working side-by-side with our colleagues in South Africa, particularly Professor Sahar Abdul-Rasool and also our colleagues in the School of Nursing, Professors 'Yinka Adejumo and Karien Jooste, is always a most rewarding experience.

I have repeated here the aims of this UMSAEP application and our actions in achieving these aims prior to, during, and following the November 4-17 visit to Western Cape.

First, we aim to study: (1) the role of genomic variants in the observed inter-individual variation in the onset, sensitivity, duration, and severity of symptoms of LE following breast cancer treatment [and, potentially, responses to therapies designed to prevent, alleviate, or eliminate these symptoms], and (II) the role of non-genomic influence(s) such as cancer treatment, body mass index, co-morbid conditions, and problem-solving, that may potentially mitigate the effects of genomic variants in symptom manifestations and/or response to treatment. Specific study aims are: We will: (1) Collect genetic, historical, and anthropometric data on breast cancer survivors with and without lymphedema among our collaborating breast cancer and lymphedema clinics of the Western Cape; (2) Using standard molecular genetics, examine both rare and common genetic variants potentially associated with variation in symptom manifestations of LE in breast cancer survivors; (3) Examine phenotypic and genotypic variation in secondary LE emerging following cancer treatment; and (4) Examine associations between LE phenotypes among breast cancer survivors with LE and a) genomic factors; b) non-genomic factors such as cancer treatment, BMI, co-morbid conditions; and c) psychosocial variables such as problem solving. We will utilize state-of-the-science PCR and DNA sequencing to examine potential genetic mutations. We will study the phenotypes of post-breast cancer LE (early-late onset, chronic-acute-transient, whole/segmental limb, limb-trunk, mild-moderate-severe, low-high distress) and their associated genomic and non-genomic influences.

As noted in the report by Prof Sahar, genetic specimens have been collected from breast cancer survivors with and without lymphedema and healthy controls for examination of genetic associations between those developing lymphedema following breast cancer. We have added anthropometric and treatment history data to the data set. Initial genetic analysis has been done and a manuscript reporting the findings is near-final. We will send it for an external review by a colleague in Arizona who works in a lymphedema genetics lab prior to submitting to a peer-reviewed journal. Sahar has presented about the study findings in Columbia in July and in CapeTown in November. Sahar anticipates the arrival of a graduate student from Libya this semester; this funded position will help the project move forward with collection and processing of more specimens. In Missouri, we are validating the extraction protocol to lessen contamination in processing of the salivary specimens, necessary with the high sensitivity of the

Illumina GWAS platform we use. Overall, we expect two collaborative peer-reviewed scientific papers from this work; one on findings and one focused on the rationale for the genetic research.

Manuscripts in development related to the 2014 UMSAEPS (Abdul-Rasool and Armer exchanges):

Abdul-Rasool, S. & Armer, J.M. (in development). [Preliminary single-study findings on lymphatic system-associated genetic mutations in post-breast cancer lymphedema.] *Current Cancer Therapy Reviews*.

Abdul-Rasool, S. & Armer, J.M. (in development). [Future implications of the genetic work on prevention, risk-reduction, and management of post-breast cancer lymphedema.] *Journal of Personalized Medicine*.

Both manuscripts will be submitted for 2015 special issues on long-term cancer survivorship. The support of UMSAEP is helping to advance our collaboration and move us toward a major multisite grant application for further study of genetic associations in secondary lymphedema.

Secondly, we will consult with and further the development of lymphedema management training and a national lymphedema framework in South Africa under the partnership with University of Western Cape. To this date, 72 lymphedema therapists have been trained in Best Practices of lymphedema management in 135-hour courses through a partnership with UWC, MU, and Norton School of Lymphatic Therapy in the US. The aim is to continue to build the foundation for a self-sustaining, South African-based lymphedema training program in UWC CENTALS. Initial steps have been taken in initiating the Lymphedema Association of South Africa (LAOSA), a national framework for lymphedema education research, and practice modeled after the American Lymphedema Framework Project (ALFP) founded by the applicant and her professional colleagues in the US. We aim to nurture and sustain this organization now in its infancy through a national stakeholder meeting and consultations.

In my first day on the ground, November 6, I met with UWC SON Professors Jooste and Adejumo, Ms Sonja Walker, UWC clinical faculty and graduate of our 2010 lymphedema class, to review our status in training plans and brainstorm further areas of collaboration. We are finalizing the Memorandum of Understanding we have edited by email and will soon review and sign a final copy for 2015-2017 training plans. This MOU spells out areas of responsibilities among the three parties: University of Western Cape, University of Missouri, and Norton School for Lymphatic Therapy. We hope to finalize this in February 2015 after the scheduled meeting of the UWC CENTALS board. We hope to offer a lymphedema training class in late 2015/early 2016. A class will accommodate 18-20 students and we have 44 professionals on a wait list. We strategized about the possibility of holding two parallel classes to accommodate up to 40 students. Participating in this meeting was a colleague from the US, Ms. Julia Rodrick, an expert trainer in lymphedema therapy and adjunct faculty with MUSSON, who accompanied me in order to learn about our training program in South Africa and meet our UWC colleagues, as well as to lead two advanced lymphedema workshops which we designed for the graduates of our earlier classes. Julia may return as our trainer at the next course, if dates are compatible with her schedule.

On the afternoon of November 6, Prof Rasool provided a tour of her lab and accompanied us to Prof David Fisher's office for a most informative overview of sciences on the UWC campus. On the evening of November 11, we enjoyed dinner with Prof Fisher and his wife, Sahar and her daughter, and Julia and myself. Among these and the next reported activities, we were available

to consult with patients and therapists treating patients with lymphedema. We carried and distributed two large suitcases of donated lymphedema patient supplies and materials for the workshops to be used for lymphedema management.

On Tuesday, November 11, Ms. Sonja Walker presented the findings of her South Africa web-based survey of trained lymphedema therapists at the International Women's Health Conference in a session chaired by Prof Adejumo. Ms. Walker used the survey developed and twice launched in the US by the American Lymphedema Framework Project, which I co-founded and currently direct (and which is based at University of Missouri). This research is a part of her dissertation research at UWC; I sit on her PhD committee as co-advisor with Prof Adejumo. This work will lead to a refereed publication as her dissertation progresses. Sonja is funded to join us in Missouri for one month in 2015 as part of an UMSAEP exchange to further her knowledge in lymphedema management, education, and research.

On the same day at the same international conference, Prof Lize Maree, Director of School of Nursing at Wits University and also a graduate of our first lymphedema course in 2008, presented findings from her research in gynecological cancer, and I presented the update on the American Lymphedema Framework Project's accomplishments, including the building of a minimum data set and the completion of 9 systematic literature reviews to guide evidence-based practice in the management of lymphedema. Julia Rodrick and another training graduate Dorethea Van Schoor accompanied me to the conference.

Refereed presentation from this UMSAEP visit:

Armer, J.M., Feldman, J., Stewart, B. R., Smith, K.M., Cormier, J.N. (November, 2014). Maintaining Best Practices Through Evidence-Based Lymphedema Treatment Guidelines: Findings from the American Lymphedema Framework Project Systematic Review. Paper presented at the International Conference on Women's Health Issues, Cape Town, South Africa. (international)

On Thursday, November 13, we held the first of two advanced training workshops in lymphedema led by Julia Rodrick, OTR, CLT-LANA, at the physiotherapy clinic at Groote Schuur Hospital. This workshop was on Aquatic Lymphatic Therapy and included both classroom and pool demonstration in the hydroelectric pool at GSH with therapists and patients. The workshop was a resounding success. About 20 professionals earlier trained by us in lymphedema management attended the full day activities and received a certificate of completion with CDT points. Working with therapists we have trained in South Africa, the workshop and stakeholder planning committee was composed of three of our graduates (Dorethea Van Schoor, Isla Muhl, and Rogini Pillay) and Julia and myself at a distance. Flyers and agenda are available upon request.

On Saturday, November 15, we held the second of the two advanced workshops led by Julia in a training facility near the University of Western Cape, in Brackenfell. This workshop was on advanced elastic taping techniques to complement other modalities of complete decongestive therapy. Again, about 20 therapists attended this day and received both didactic and hands-on instruction in elastic taping. We also scheduled several patients to come for assessment and treatment by Julia under the observation of the students. This too was a resounding success.

On Friday, November 14, the day between the two workshops, we held a South Africa Lymphedema Stakeholder day in collaboration with LAOSA, our trained therapists, and an industry partner who had recently built a training/storage facility in Western Cape in Brackenfell. The Stakeholder day was made up of scientific presentations, including two by me on (1) the ALFP minimum data set and mobile device for limb measurement, and (2) genetics of primary lymphedema; one by Prof Sahar Abdul-Rasool on genetics of secondary lymphedema and our preliminary research; one by Julia Rodrick on the ALFP systematic reviews, focusing on complementary therapies; and one by Sonja Walker on her research findings from the web-based therapist survey, among others. The history of the lymphedema management and training in South Africa was recounted by one of the earlier therapists in South Africa, Isla Muhl, highlighting the partnership with MU and UWC which has led to the accomplishments of today. After the morning of scientific presentations, we moved into the open-space meeting format we previously used in our ALFP meetings in the US, wherein small working groups discussed and prioritized issues in lymphedema in South Africa and then strategized on solutions, before reporting back to the larger group. We have pre-post survey data which we will summarize and share with participants and on our website, as well as formally report in a manuscript and to policy makers. It was a highly successful day with much interaction and positive energy toward moving forward. Attendees came from all parts of South Africa, including four from J-burg, and others from East London and Hermanus. Approximately 25 attended the full day.

We have held a modified stakeholder day as we graduate each UWC lymphedema training class and plan to do so again in the future. We also now have an established network for web-based communication and surveys which will serve us well in the future. We look forward to implementing strategies from the stakeholder day and planning future such meetings to assess benchmarks in our progress.

I share here an excerpt from a communication following the workshops and stakeholder days:

From: Isla Muhl [mailto:isla.muhl.35@gmail.com]
Sent: Monday, November 24, 2014 10:54 AM
To: Armer, Jane
Cc: Julia Rodrick
Subject: Re: South Africa and ALT at GSH

Dear Jane and Julia

What a wonderful opportunity we had to have you both here in Cape Town!

It was so generous of you to represent the ALFP and give so much enthusiastic, dedicated and intensive input over 3 full days (..... and many hours before and subsequently).

It was a stimulating and encouraging time for our lymphoedema community and the fruits will help many patients, and stimulate us to move forward, I'm sure:)

I do hope that you've both managed to get some rest

My best to you both

Love

Isla Muhl (2008 lymphedema graduate and co-planner for the workshop and stakeholder days)

We have a growing number of publications from our UMSAEP exchanges, with two being 2014:

Stout, N., VanSchoor, T., Armer, J. (2014, in review). Promoting Lymphedema as a Chronic Disease in South Africa: Aligning Best Practice and Policy. *Lymphology*.

Armer, J., Stadler, L., van Schoor, D. (2014, in press). The search for answers about diagnosis and management of lymphedema in South Africa. *Journal of Lymphedema*.

Dine, J., Schneider, M. & Armer, J. (2011). Nursing education on lymphedema self-management and self-monitoring in a South African oncology clinic. *Journal of Cultural Diversity*.

Armer, N., Armer, J., Stout, N., Parker, V., Schneider, M., Norton, S., & Stewart, B. (2010). Establishing a means to assess cross-cultural teaching and student learning of critical lymphedema management curriculum. *Lymphology*, 43(Suppl), 245-249. Proceedings of 22nd biennial International Congress of Lymphology, International Society of Lymphology. (international)

Each of these publications include as authors trainees and/or trainers from our South Africa collaboration. In addition, at least one publication has emerged written independently by three of our graduates (Marcos, Pillay, Schoonheim), based on preliminary work we have done together following their training. Other graduates have developed and shared lymphedema case studies.

While meeting with Professors Jooste and Adejumo, I invited them and their faculty to submit manuscripts to the two special issues I will be guest editing this Spring in *Journal of Personalized Medicine* and *Current Cancer Therapy Reports*. During our meeting, Prof Jooste asked me to request of the publisher an opportunity to jointly edit a special issue among her, Prof 'Yinka, and myself. I acted upon this request and have obtained a commitment for a special issue of *Journal of Personalized Medicine* in areas related to public health collaboration with 6-12 manuscripts solicited for June 2015 for publication in 2016. This will be a significant accomplishment in collaborating across the miles between our institutions.

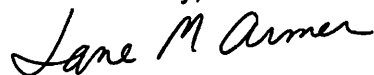
Following our meeting, we are also brainstorming about additional ways to maintain the profile and visibility of UWC as a leader in the lymphedema community in the Western Cape and South Africa (and the continent). This communication continues by email and will be facilitated by Sonja's presence here in April and my return to South Africa later in 2015. Prof 'Yinka and Prof Jooste each hope to visit Missouri in 2015. Julia and I are examining the feasibility of launching web-based modules or readings with CE credit to support our 72 trained therapists and begin the training of those on the wait-list and other interested professionals.

In summary, the UWC-MU partnership in the field of lymphedema education and research is thriving and recruiting new members to the partnership, as well as making significant impact on the lymphedema and greater community. I again thank you for this opportunity and support for this important and rewarding work.

Pending funding support from the balance of the UMSAEP award, I hope to return to Western Cape later this year to continue the genetics research collaboration, comparing findings between our two studies, and, depending on the timing, to participate in implementing the strategies identified in the stakeholder meeting and/or help evaluate initial implementation and guide the next stakeholder processes.

Please do not hesitate to contact me if further information is required or desired.

Most sincerely,



Jane M. Armer, PhD, RN, FAAN, CLT
Professor, Sinclair School of Nursing
University of Missouri