

# SWOG Latin America Initiative NEVSLETTER



THE HOPE
FOUNDATION
FOR CANCER RESEARCH

Strengthening Relationships for Latino Cancer Patients

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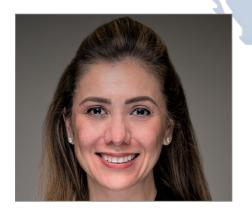
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A Word From the SWOG Executive Officer for International Affairs

## Dear Readers,

SWOG's Latin America Initiative (SLAI) represents a long-standing effort to strengthen capacity and excellence in clinical research trial design in the region, to include and promote interaction between investigators, and to establish strong academic relationships. Our midand long-term aim is to address the cancer burden among Latinos/ as—not only in Latin America but also in the US, where they are the largest minority population yet represent only around 1% of patients registered in clinical trials. We envisage this initiative as an integral component of a broader strategy that pursues the reduction of cancer inequities in the US and the Americas as a whole.

We have created this newsletter to disseminate our accomplishments and to ensure that SWOG investigators are familiar with the potential opportunities to activate trials in our sister sites in Mexico, Peru, Chile, Colombia, Uruguay, and Brazil. This inaugural issue of our newsletter highlights summaries of the presentations of our SLAI Symposium during our spring meeting in Seattle. The symposium focused on cancer inequities in research, opportunities for scientific collaborations for non-US



investigators within SWOG, and highlights from the SLAI sites.

We are looking forward to more collaborations and you getting to know more about the sites, investigators, and team members in Latin America!

Sincerely,

Mariana Chavez Mac Gregor, MD, MSc

Mariana



**ABOVE: Countries with SLAI institutions** 

**BELOW: SLAI Group Social, April 2022** 



Every project has an origin story, and most of what we at SWOG and CRAB can remember begins with Dr. John Crowley. Thus, it is only fitting that Dr. Crowley, CRAB co-founder and one of the early visionaries for the SWOG Latin America Initiative, relates his version of how SLAI came to be...



# The Story of the SWOG Latin America Initiative

PART ONE: SLAI PRE-HISTORY

**SWOG** has a long history of international collaboration, most notably in recent decades with institutions and investigators in Japan. Through these collaborations, SWOG had a profound positive impact on the conduct of cancer clinical trials in Japan, and the experience was personally and professionally rewarding for me. However, no Japanese institution joined SWOG and only one joint project resulted.

Being enthusiastic about international collaboration and the development of clinical trial

infrastructure, I wanted to continue in this direction and decided in 2003 to pursue collaborations in Latin America, a region with a growing cancer burden and without a US-style infrastructure for cancer clinical trials. After initial discussions with John Potter, then director of the Division of Public Health at the Fred Hutchinson Cancer Research Center and an expert in global health, I contacted Dave Alberts, the chair of the gynecologic oncology committee of the Southwest Oncology Group (SWOG), and we

roped in Robert Greenberg, former director of the Dartmouth Cancer Center and a cancer epidemiologist with extensive experience in Latin America, and Elena Martínez, a cancer epidemiologist.

Our first task was to engage Chuck Coltman, who was an easy sell. With funding from The Hope Foundation, we met twice in 2004 with US and Latin American experts to discuss ideas for possible collaboration. Bob, Elena, and I became the core of the first SWOG project in Latin America, an *H.pylori* eradication trial.

# Dr. Joe Unger Discusses Strategies to Overcome Barriers Impeding Racial and Ethnic Diversity in Clinical Research

Joseph Unger, Ph.D., statistician and faculty at Fred Hutchinson Cancer Center and the University of Washington, was invited as a featured speaker at the SWOG Latin America Initiative Symposium to discuss his research on diversity in clinical trial participation.

Referencing a 2010 Institute of Medicine report on the fifty-year history of the National Cancer Institute's National Clinical Trial Network, Dr. Unger described the extraordinary impact that the participating cooperative groups have had on clinical research over the decades. However, Dr. Unger urged that



"We know from numerous studies that, once adult cancer patients learn about clinical trials, the majority express a willingness to participate."

JOSEPH UNGER, PH.D.

additional work is required to better ensure that the benefits of newly discovered treatments in clinical trials apply to all patients with cancer.

Specifically, Dr. Unger described the barriers to broader participation by diverse racial and ethnic groups in

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# Diversity and Inclusion among Researchers, Patients, and Patient Advocates

## Dr. Bárbara Segarra-Vázquez,

SWOG patient advocate and researcher at the University of Puerto Rico, was invited to speak at the SLAI Symposium about diversity and inclusion efforts and possible paths forward.

Since 1993, the United States has instated many initiatives and mandates to increase diversity and inclusion in research. Unfortunately, the impact has not been as significant as anticipated. More than 20 years later, racial and ethnic minorities represent almost 40% of the United States population and continue to be vastly underrepresented in research trials. NCI trials in which the primary focus is racial and ethnic minorities are less than 2% (Oh et al., 2015, PLOS Medicine, 12(12)). These underwhelming statistics, coupled with a growing and increasingly diverse population, highlight the need for improved diversity and inclusion in research efforts.

The importance of diversity and inclusion in research extends far beyond enrollment in clinical trials. Enrichment of research needs to



"Diversity in clinical trials goes beyond enrollment. It extends to researchers, research teams, staff, recruiting physicians, and patient advocates."

> BARBARA SEGARRA-VÁSQUEZ, SWOG PATIENT ADVOCATE

involve researchers, research teams and staff, study sections, physicians, and patient advocates of diverse backgrounds who can contribute a wide range of perspectives and expertise in designing and implementing studies. But how can we recruit and improve representation across the research spectrum?

Advocacy and the power of advocates in giving voice to patients, survivors, and the community is a promising approach. The SWOG Cancer Research Network has been involving advocates in research since the 1990s and has since become the first NCI group to formally include advocates in trials. Advocates have

repeatedly been shown to improve engagement outcomes in studies from beginning to end of the trial. For example, insight from advocates can improve research feasibility, accrual, and retention and increase public trust through enhanced transparency and accountability.

Myths around LatinX reticence to participate in clinical trials abound. These myths are not true. After Hurricane Maria, the island of Puerto Rico was without electricity for six months. Recruitment analysis showed that while several US sites had still not recruited a single patient to TrACER, Puerto Rico enrolled its first patient in the aftermath of the hurricane.

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clinical trials that limit the generalizability of these groundbreaking studies. Dr. Unger discussed how: (i) structural barriers limit access to available trials for more than half of all cancer patients; (ii) clinical barriers, although required for ensuring the validity of trial findings, can be too restrictive and preclude participation by another one quarter of all patients with cancer; (iii) physicians may fear

that trial offerings to patients can interfere with the physician/patient relationship, and even when they do wish to offer trials to patients, often lack the resources, time, or personnel to facilitate trials; and (iv) patients may lack knowledge about opportunities to receive their care in trials.

Dr. Unger cited his systematic literature review and meta-analysis demonstrating that, once approached to participate in clinical research, Black, Hispanic, and Asian patients enrolled at rates at least as high as White patients.

"We know from numerous studies that, once adult cancer patients learn about clinical trials, the majority express a willingness to participate," said Dr. Unger. "And so we believe that appropriate interventions tailored to the above barriers will increase both enrollment and diversity in clinical trials, resulting in more impactful and representative studies."

## Lung, Breast, and Genitourinary Committee Perspectives

Lung, breast, and genitourinary cancers contribute to the high cancer burden in Latin America.

Dr. Anne Chiang, the executive officer for the lung and breast committees, and Dr. Ian Thompson, the chair for the GU committee, joined the SLAI Symposium at the spring 2022 SWOG group meeting in Seattle, where they presented on committee structure and current, past, and future studies in their committees.

Drs. Chiang and Thomas encouraged investigators outside of the US to become committee members and engage in scientific discussions, accrue to trials open to international participation, and even serve as champions for trials in other cooperative groups. The GU committee also offers mentorships for young investigators to work with senior investigators on SWOG protocols or develop translational medicine concepts.

Dr. Chiang specifically mentioned committee interest in understanding international site and SWOG processes for activating trials outside of the US. As SLAI participation within SWOG solidifies, the SLAI coordinating team continues to support SWOG committees in advancing their familiarity with external factors that influence non-US site participation and remains committed to increasing staff and patient diversity on SWOG trials.

#### **BREAST**

**\$1007:** 100 patients accrued in Mexico and Colombia, combined!

## LUNG

\$1827: Chile, Colombia, and Mexico working towards study activation \$1914: Chile waiting for CTEP approval of protocol revisions that would include their participation

### GU

**S1802:** Chile, Colombia, Peru, and Uruguay working on protocol activation. Mexico is actively recruiting patients.

# Spotlight on Chile

The Grupo Oncológico
Cooperativo Chileno de
Investigación (GOCCHI) is the SWOG
main member site in Chile and was
featured at the SLAI Symposium this
spring. Dr. Javier Retamales, SWOG
investigator and executive director
at GOCCHI, presented in person.

Joining SWOG in March 2021, GOCCHI activated S1714 within months and enrolled 10 patients by study accrual closure in November 2021. Currently, GOCCHI is waiting for authorization to participate or is working towards local activation of the following protocols: S1501, S1802, S1827, S1914, S2013, EA1151, and SLA01.

Additional requirements and expenses not faced by US sites—as

well as delays in US approvals for international participation elucidate why more time may be required to activate SWOG trials in



**Dr. Retamales** 

non-US institutions. In addition to US regulations, GOCCHI must also fulfil local regulatory requirements, such as obtaining permissions from their local ethics committees, seeking institutional approvals, and requesting Chilean Ministry of Health authorization to import or export medications, study materials, and specimens. For some trials, GOCCHI must acquire civil responsibility Insurance, guaranteeing payment to patients in case of adverse events. To participate in radiology and imaging

trials, GOCCHI has gained a wealth of experience importing phantoms for quality assurance. Some staff at IROC know Dr. Retamales by name!

Nevertheless, for Dr. Retamales, SWOG offers Chilean investigators the opportunity to participate in collaborative research and become involved in multidisciplinary trials. GOCCHI has two sub-affiliate sites in Santiago: the Instituto Nacional del Cáncer (National Institute of Cancer) and the Hospital Sótero del Rio. As Chile gains experience with SWOG trials, Dr. Retamales has plans for GOCCHI's SWOG activities and number of its sub-affiliate sites to also grow. As he puts it, Chilean patients and medical professionals have everything to gain by strengthening local cancer knowledge, increasing life years, and saving lives.

WANT TO LEARN MORE?

To view the SWOG Latin America Initiative Symposium in full and learn more about Latin American institutions' participation in SWOG activities, please watch the recorded version here:

SWOG Spring 2022 Hybrid Group Meeting: SWOG Latin America Initiative Symposium - YouTube