

The Sustainable Sciences Institute (SSI) is an international non-profit non-government organization dedicated to developing scientific research capacity in areas of the world with pressing health problems. Our work is based on the premise that global health relies on biomedical scientists and public health workers who recognize and resolve priority disease problems at the local level with the appropriate use of knowledge, science, and technology. To this end, SSI works with partners and collaborators around the world to bring science to where it's needed most to combat priority public health problems in limited resource settings.

## OUR APPROACH

We help biomedical scientists and program directors gain access to training, funding, information, equipment, and supplies so that they can better meet the public health needs of their communities at the local, national and regional levels. We identify and work directly with promising researchers (and by extension their institutions) in developing countries, offering professional mentoring and long-term assistance to support them in their fields of research, share and pass on critical skills to their networks of colleagues, and identify ways in which they can continue to make a critical difference in the health of their own communities.

**\$300K** awarded in small seed grants to promising scientists and public health researchers in developing countries

over **\$1 million** donated in equipment to **23 labs** in Latin America and Africa

SSI aims to strengthen local scientific capacity, to reduce inequalities in health research, to facilitate knowledge exchange, to build networks of peers, and to support sustainable research efforts through the creation of Centers of Excellence. Our capacity building approach is based on four pillars: Training, Material Aid, Small Grants, and Networking and Consulting. We first train researchers through in-country workshops and provide donated laboratory materials. After the workshop, participants can apply for a small grant from SSI (depending on available funds) to continue their research using the new skills they learned. During and after the workshop, we help build partnerships, make connections between researchers locally, regionally, and internationally, and provide long-term support to our participants.

As an organization, SSI is an active advocate for open access science and socially responsible research and innovation. We believe and promote that sharing scientific progress and making resources and tools available to local partners on the front lines of public health problems is the only way to fundamentally address health equity issues. Since our inception in 1998 (and before that through SSI's predecessor as the *Applied Molecular Biology / Appropriate Technology Transfer Program*) we have transferred knowledge and technology to local scientists in the developing world through intensive in-country workshops and trainings on topics:

- Research Design and Scientific Rigor
- Scientific Proposal Preparation and Manuscript Writing
- Bioethics and Ethical Conduct of Research
- Epidemiology Methods
- Bioinformatics
- Molecular Biology Laboratory Techniques
- Good Laboratory and Good Clinical Practices
- Impact Evaluation in Public Health
- Information and Communication Technologies (ICTs) for Public Health

**75** workshops facilitated with **1,789** public health professionals trained from **29** countries in Latin America and Africa

**100+** publications in top scientific journals have directly resulted from SSI mentorships

## IMPACT: TRAINING & CAPACITY BUILDING PROGRAM

Over decades of collaborations and partnerships with colleagues (many of whom were former trainees!) at research institutions and ministries of health in Latin America and Africa, there are several specific examples of where SSI's trainings and researcher support have led to direct impact on helping to identify, respond to and control priority infectious disease outbreaks.

### ***Differential diagnosis of dengue & leptospirosis***

In 1995 in Nicaragua, there was an outbreak of a disease that clinically acted and looked like dengue. It was widely diagnosed as dengue but specimens, tested by past SSI workshop participants working for the Ministry of Health in Nicaragua, were negative for dengue virus by RT-PCR. Subsequently, specimens were found negative in serological tests, as well. There was also an absence of *Aedes aegypti* mosquitos, which transmit dengue. This led these same researchers to investigate other causes. An international team that included SSI trainees discovered that the illness was caused by a bacterium, *Leptospira*, which is treatable with antibiotics. Leptospirosis was then recognized as a major emerging disease in Latin America.

### ***Critical containment of dengue outbreaks***

In August 2001, SSI conducted a training workshop in molecular and virological techniques for the identification of dengue, tuberculosis, and leishmaniasis in Asuncion, Paraguay. A few months later there was a large outbreak of an unknown febrile illness in Paraguay. Participants from SSI's workshop, who were working for the Ministry of Health, used techniques they learned in the workshop to quickly identify the mystery illness as dengue. The rapid detection capacity and subsequent response led to better epidemiological control of the epidemic and slowed the outbreak down. This same situation happened in 2004 in Lima, Perú. Shortly after an SSI workshop on dengue identification, there was a large dengue outbreak that was successfully and rapidly identified by our former trainees. We have had trainees from Ecuador, El Salvador, Bolivia and Guatemala who have all provided critical lab skills in efficiently identifying dengue earlier in outbreaks, reducing the time necessary for public health officials to take necessary control and intervention measures.

### ***Rapid identification of RSV in an ILI outbreak***

In 2008, there was an influenza-like illness (ILI) outbreak in Nicaragua of unknown origin. The pediatric wards in hospitals quickly filled with hundreds of severe cases and numerous infant deaths were reported in the early days. The SSI team in Nicaragua immediately offered support to the Ministry of Health and began processing specimens for several of the ILI cases by RT-PCR, while additional support from the CDC was being sought. By the time the CDC team arrived the etiologic agent had been identified as respiratory syncytial virus (RSV) by the SSI team and the labs furnished with loaned reagents and kits from SSI to further process specimens.

### ***Anticipation of Influenza A H1N1pdm***

In anticipation of the Influenza A H1N1 pandemic in 2009, the SSI Nicaragua team set up a real-time RT-PCT to detect H1N1 in May of that year. The first H1N1 case in Nicaragua presented in the SSI cohort study on June 1, 2009. The SSI team advised the Ministry of Health on surveillance procedures and diagnostic strategies for the pandemic and significantly contributed to improved surveillance and detection at a critical phase of the epidemic.

### ***National Hepatitis C Biorepository in Egypt***

In 2014, SSI, in collaboration with Menoufeya University's National Liver Institute (NLI), the only academic institute in Egypt to solely focus on hepatology, set up and staffed the largest liver disease biorepository in Egypt. Over 500 hepatocarcinoma samples have already been collected and stored for research use. The National Liver Institute – Sustainable Sciences Institute Collaborative Research Center (NLISSICRC), which houses the liver biorepository, is headed by Dr. Sameera Ezzat, a former SSI trainee.

### ***Chikungunya virus preparedness 2013-2015***

In late 2013, Chikungunya, a disease similar to dengue, first appeared in Latin America. It spread rapidly from the Caribbean to Central and South America. The SSI team in Nicaragua, in collaboration with colleagues at the Ministry of Health and local research institutions, developed a strategy early on to help support local and regional detection. In January 2014 positive controls and primers for RT-PCR were obtained and set up in the national reference and diagnostic laboratory. From March to June 2014 monoclonal antibodies and antigens were obtained for in-house serological diagnosis and new ELISA assays were developed in collaboration with the Ministry of Health's National Virology Laboratory. In July 2014 the first cases of Chikungunya were

successfully and efficiently diagnosed in Nicaragua. In October 2014 the first autochthonous cases were diagnosed in Nicaragua, including participants in SSI's cohort study. By November 2014, Chikungunya samples were sent to UC Berkeley for sequencing. Currently, the outbreak has spread, with thousands of locally transmitted confirmed cases in Nicaragua. That multiple samples were sequenced very early on in the outbreak allowed researchers to effectively get out in front of this new epidemic and improve the response time, diagnostic capacity and treatment intervention effectiveness of the public health system. SSI's impact in supporting high quality research early on in disease detection in this case led to a formal collaboration with the *Pan American Health Organization* of the United Nation's World Health Organization (WHO) for regional infectious disease research capacity building.

## IMPACT: ICTs FOR HEALTH PROGRAM

Since 2004 SSI has been working with various information and communication technology (ICT) tools to support clinical and epidemiological data management needs for multiple basic research studies in our Nicaragua office, in collaboration with the Nicaraguan Ministry of Health (MoH) and various other research institutions.

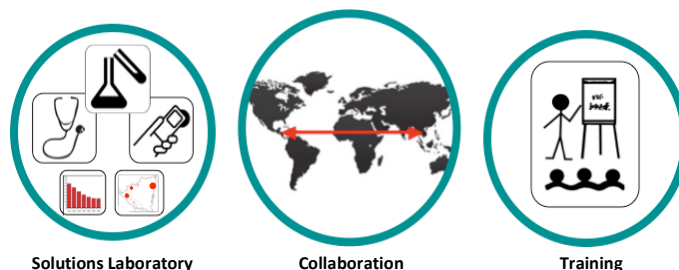
The goals of this work are to:

- 1) identify and test low cost *eHealth* solutions, primarily (but not exclusively) those that integrate open source platforms and software,
- 2) evaluate the potential impact of these tools in improving information collection, management and use to affect public health outcomes in underserved communities,
- 3) strengthen local capacity (and networks) in the *eHealth* sector in the developing world to promote knowledge exchange around sustainable practices

Low-cost ICT tools currently in use in our projects include

- mHealth tools - mobile phones, tablets, and personal data assistants (PDAs) for use with community health worker decision support, in-field data collection, household health visits, and research study participant tracking; Software that we have worked with includes *CommCare*, *OpenXData*, *OpenDataKit*, *OpenMRS-JR*, *Pendragon Forms*, and *EpiSurveyor/Magpie*
- web-based project and information management tools (Redmine, groupHub, Google groups/projects)
- barcode patient and biological sample identification and tracking systems
- patient fingerprint identification systems
- GPS data collection tools and GIS analysis software for patient/case and disease outbreak tracking
- electronic medical record systems (*OpenMRS*, *OpenClinica*, *MS Access*-based)
- laboratory information management systems
- voice-over-internet software (skype)

In various combinations, these ICT solution components have facilitated information management and decision making, improved data quality for natural history and disease epidemiology data, and allowed better compliance with *Good Clinical Practice* and *Good Laboratory Practice* standards for several research studies. In 2008 SSI formalized our eHealth program and we work on a wide range of projects related to ICT for Health, based out of our *Center of Excellence* in Nicaragua.



As part of our Nicaraguan Center of Excellence, SSI's ICT Program team also works actively on projects in our "Solutions Laboratory" with various local partners to identify, analyze, adapt, modify, test and evaluate additional *eHealth* and *mHealth* tools relevant for primary care and public health needs. Our current projects include work with:

### ***Integrated Tool Kits for Infectious Disease Surveillance, Reporting and Outreach***

As part of the Dengue FIRST initiative (**F**ighting **I**nfections through **R**esearch, **S**cience and **T**echnology), this project is a unique collaboration between SSI, partners at the Division of Infectious Diseases and Vaccinology at the University of California, Berkeley, and the Ministry of Health of Nicaragua (MINSa). We are developing and

testing 3 low-cost information and communication technology (ICT) tools to help improve laboratory, surveillance and clinical management practices to reduce dengue-related morbidity and mortality. Currently, no other comprehensive ICT tool kit to help address this critical disease exists and the goal with this project is to create a suite of tools that can be tailored for systems in other countries to improve local health systems worldwide.

**Laboratory Information Management Systems** – SSI designed, developed and implemented an integrated Laboratory Information Management System (LIMS) in collaboration with the CNDR/Ministry of Health in Nicaragua and the associated 6 regional laboratories using an open source web-based system. This system, originally developed in 2010 and under regular adaptation according to user demand at the CNDR, includes sample reception, tracking and management history, integration of automated diagnostic equipment data, results reporting tools for integration with various patient information management systems, and inventory management tools.

**Mobile Technologies (mHealth)** – Since 2008 we have been actively involved at the forefront of mHealth research in Latin America where we have worked on a range of projects that incorporate the use of mobile technologies in laboratory, health center/clinic, and community-based care in limited resource settings.

- ***Research Support, patient tracking, biological sample collection and data management***  
In SSI's ongoing research studies on dengue and influenza in Managua, we have worked closely with team scientists to design a suite of mobile health data collection tools for participant tracking, biological sample management, household follow-up visits by clinicians and epidemiologists, and interactive appointment reminder and outreach educational messaging tools for engaging participants and their families. Our health-center based research team uses a range of hardware (tablets and mobile phones) to document informed participant consent, validate and verify participant identification and biographic information, document and capture biological sample management information using barcode identification and collect a wide range of survey information at the household level about participants and their health behaviors and risk factors.
- ***Community-level Disease Surveillance & High Risk Pregnancy Tracking***  
With the Nicaraguan Ministry of Health we have developed a community health worker surveillance tool to complement existing work flows around tracking and referrals for reportable diseases as well as high risk pregnancies and other high priority health conditions, both chronic and acute. This *Vigilancia Comunitaria* tool (a cross-platform application that can be used on a wide range of low-cost internet-enabled hardware devices) is currently being scaled for use by over 1500 community health workers in 3 state health departments in Nicaragua, with the goal of being used nationally within the next few years.

**Collaborations, Knowledge Sharing & Strategic Guidance** - SSI supports knowledge-sharing networks with similar organizations, institutions and health resources in and between developed and developing countries, particularly focusing on South-South collaborations. SSI helped to found the Informática Médica Código Abierto (IMECA) community for Open Source Health Informatics in Latin America - <http://www.informaticamedicalac.org/>. Along with *Partners In Health*, we co-coordinated the 1<sup>st</sup> annual IMeCA meeting and workshop series in Lima, Peru, in October 2009. In November 2010, SSI and *eHealth Systems* (Chile) hosted the 2<sup>nd</sup> annual IMeCA meeting in Granada, Nicaragua. 70+ people from 17 countries participated in 5 days of presentations and workshops sharing lessons learned about open source *eHealth* technologies. We continue to help moderate the group list and connect stakeholders in the region.

SSI serves in a guidance role to several offices of the Ministry of Health of Nicaragua, the Immunization Section of the Pan American Health Association (PAHO) and various other regional stakeholders about implementing health ICTs. This support is based on the lessons learned from SSI's experience and those of our counterparts and partners working in the *eHealth* field.

**Workshops and Training Curricula** - In line with SSI's capacity building and training focus, the ICT for Health Program has developed training materials around several critical content areas for eHealth and mHealth implementations and research in Latin America.

- *eHealth* needs assessment, policy frameworks, and decision-making support tools
- monitoring and evaluation for *eHealth* and ICT for Health impact
- technical skills for EMR, LIMS, and *mHealth* tools development and implementation