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## CKDu: Strategies for Saving Lives Now

Jason Glaser and Ilana Weiss MA MPH, on behalf of La Isla Foundation

La Isla Foundation (LIF) is a nongovernmental organization based in Nicaragua that works at the intersection of health and human rights. LIF was created to address the fatal epidemic of chronic kidney disease of nontraditional causes (CKDu) in the context of its impact on sugarcane workers in Central America. In the town of Chichigalpa, the epicenter of the Nicaraguan epidemic, mortality from CKDu has more than doubled in the last five years. Municipal records show that about 46% of all male deaths between the years 2002-2012 were due to CKDu. So many have perished from the disease in the Chichigalpa community of La Isla, that locals have come to refer to it as *La Isla de Viudas* or “The Island of Widows.”

Current research suggests that physiological pathways triggered by heat stress and chronic dehydration, due to grueling labor conditions, are primary drivers of this epidemic. Damage to the kidneys is believed to be exacerbated by exposure to environmental toxins, among them agricultural chemicals, and the metabolism of sugar in the state of dehydration.

However, most important is that this disease does not exist in a vacuum: policies carried out, or in some cases, not adhered to, by lending institutions, governments and corporations put the vulnerable populations impacted by CKDu at increased risk. A multidisciplinary, multilayered strategy is paramount to adequately address the CKDu epidemic. Conscious of this, LIF has developed four operational pillars:

**Pillar 1: Public Health.** Coordinated laboratory and fieldwork to identify the physiological and epidemiological drivers of CKDu, leading to evidence-based interventions that can help affected communities now.

**Pillar 2: Law and Human Rights.** Analysis of rights and labor abuses in the context of the epidemic, motivating effective advocacy and policy change implementation.

**Pillar 3: Community Development.** Direct support for vulnerable communities, important both to limit study fatigue and to address immediate needs.

**Pillar 4: Media & Communications.** Engaging a broad base of international support for interventions, among sugar consumers, workers and producers is essential. This is not possible without adequate and responsible media coverage. Given that industry is funding much of the critical research into the epidemic, the role of responsible media cannot be overstated. When respected news organizations shine light on the situation, a fuller range of research results and viewpoints are showcased, inspiring more diverse funding as well.

Thanks to greater public engagement with the issue due to deeper press coverage, further research, the creation of the Consortium on the Epidemic of Nephropathy in Central America and Mexico (CENCAM), and declarations from both PAHO and the Central American Commission of Health Ministries, a broader and more dynamic discourse is now ongoing.

However, research on the epidemic faces undue influence from vested interests. When public health concerns do not align with corporate or political agendas, study design and results often suffer as consequence. For example, thus far the sugar industry has been one of the largest funders of research into CKDu in Central America. It is noteworthy that while virtually all independent investigations have acknowledged a major occupational component linked to the disease, industry-funded research to date does not. We believe that such research, *including work receiving funds but not yet conducted*, is being used by the sugar industry to defend and protect its own interests. Our fear is that this will continue to happen as the Central American sugar industry sponsors more studies, endangering the objectivity of research. Already, Mario Amador, general manager of Nicaragua’s National Committee of Sugarcane Producers, concluded in an article published by the Center for Public Integrity: “We are fully convinced that there is no direct relationship between CKD and the activities conducted in the sugarcane industry...A sign of our good faith and our conviction about this is the support we give to scientific studies.”[1]

Yet, given the current understanding of the disease, we believe there is a window of opportunity for industry to protect the workforce and in doing so, mitigate its own liability. However, this requires acknowledging the links between workplace practices and the disease. Industry players who are brave enough to take measurable and evaluable steps to implement work practice interventions should be applauded and publicly supported. Their actions can encourage others to take similar steps and become early adopters of progressive worker health policies.

Especially important is to engage the health and labor ministries in affected countries. They will be best able to implement fresh policies needed to ameliorate the epidemic and its effects. History is full of examples where prevention and regulation are delayed by directing research away from the most compelling evidence. To avoid this happening with the CKDu epidemic, the scientific community must have the courage to look beyond personal research interests and worries about offending some of the dominant funding sources. In particular, a public statement is essential from those groups that acknowledge that we know enough about the disease to intervene now on occupational issues in the sugarcane industry.

LIF is currently planning and executing its research and advocacy agenda for the next three years, to culminate in a conference that brings together researchers and stakeholders in a public forum to share lessons learned and the latest findings. The aim is to determine together how to institutionalize best practices in the realms of public health, health provision, community participation and occupational health and safety so that public and private institutions may more effectively prevent and treat the disease.


Looking ahead to this conference, LIF would like to offer ideas about a coordinated way to move forward. Our starting point is to place the needs of the affected population first, and then, follow the science as it unfolds—a strategy we believe will also assist

in closing some of the current divisions among research groups. Specifically, we propose:

1. **Achieving transparency in research agendas:** By understanding what each research group is undertaking, we can better complement and coordinate our efforts. For its part, LIF will be focusing on the synergy between toxins and pathways related to dehydration and heat stress via laboratory work, and studies involving both worker and community cohorts. Our primary focus will be an evolving, and constantly improving, workforce intervention program with input from PAHO, OSHA's Heat Illness Prevention Campaign (Water. Rest.Shade), CDC, NIOSH, the labor ministries of affected countries, industry and representatives from the impacted communities. We welcome collaboration and insight from other groups.
2. **Coordinating Funding & Research:** The effect of the disease on lives and economies is dire. In a limited-funding environment, a push towards collaboration and trust is essential. That goal is only realistic if rigorously tested hypotheses, such as those regarding the impact of pesticides or damage due to pathways triggered by heat stress, are not viewed by researchers as mutually exclusive or somehow undermining of one or another party's work. Efforts should be made to pool resources where possible, to generate comparative studies, and to integrate research in order to most effectively use the resources at hand, while creating funding models that reflect a coordinated research strategy.
3. **Sharing of information and encouraging broad discourse among researchers through PAHO and CEN-CAM:** Though differences of opinion will always exist, they are a valuable part of the scientific process and necessary to arrive at reliable findings. PAHO, given its commitment to addressing the epidemic and its relationship to health ministries of impacted countries must be utilized as a convening body so a more effective and unified strategy can evolve.

CENCAM can also encourage a more robust dialogue and a commitment to addressing the work practices associated with the disease.

4. **Engaging industry, health ministries and labor ministries:** The fear of liability and repercussions must be somehow overcome and this will require coordination and collaboration. The epidemic in Central America has been allowed to grow beyond the resources of any one party to address it. Health ministries, such as the Ministry of Health in El Salvador, should be lauded for taking action and demonstrating a vision that has been unequaled in the region. Others should be encouraged to follow suit.

**First Things First** In the research community, there is consensus that sugarcane workers are the most affected population in the most-studied countries, El Salvador and Nicaragua. Most researchers also agree that the epidemic's cause is multifactorial and merits further investigation. In the interim, however, the evidence points towards workplace interventions that could prevent and/or slow onset and progression of the disease. This does not diminish the need or importance of further work into specific etiological components of CKDu, but ethically we are bound to save lives when and where we can. By making a workplace intervention a first step forward, we open the door to the collaboration needed to further understand and eventually end this epidemic. 

1. Chavkin S. CDC launches industry-financed studies of deadly kidney disease in Central America. Center for Public Integrity [Internet]. 2014 Feb 12 [cited 2014 Mar 13]; [about 3 screens]. Available from <http://www.publicintegrity.org/2014/02/12/14236/cdc-launches-industry-financed-studies-deadly-kidney-disease-central-america>

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