Real World Evidence in Action

Piga Fernández
Executive Director Fundación GIST Chile
LRG Global Relations Coordinator
PARTNERS

Chilean Society of Medical Oncology

Support Team for Oncological Research & Medicine

The Life Raft Group
INTRODUCTION

Where I was, where I am now

2014 - Observer

Patient advocates, journalist

2019 - Protagonist

Patient advocates, Senator Carolina Goic and President Sebastián Piñera
HOW DID I GET THERE?

1. “Being in the right place, at the right time and meeting the right people”

- Finding and working with The Life Raft Group
- Being part of Alianza GIST
- Meeting a GIST Specialist – Dr. Marcelo Garrido
- Being invited to be part of the National Cancer Forum Foundation – Meet Senator Carolina Goic
HOW DID I GET THERE?

“Being in the right place, at the right moment…”

53rd Directing Council of the Pan American Health Organization (PAHO),
66th Session of the Regional Committee of the World Health Organization (WHO) for the Americas.

Washington, DC, United States of America,
September 29 to October 3, 2014.
HOW DID I GET THERE?

...... *and meeting the right people*”.

Dr. Marcelo Garrido

Senator Carolina Goic
HOW DID I GET THERE?

2. “With Passion”

World Health Organization (WHO) @WHO · 6 abr.
“Health is a human right. No one should get sick and die just because they are poor, or because they cannot access the health services they need.”

Support #HealthForAll who.int/petition

Traducir Tweet

"HEALTH IS A HUMAN RIGHT. NO ONE SHOULD GET SICK AND DIE JUST BECAUSE THEY ARE POOR, OR BECAUSE THEY CANNOT ACCESS THE HEALTH SERVICES THEY NEED."

Dr Tedros Adhanom Ghebreyesus, Director General WHO
GOALS

• ACCESS to GIST treatments through the “Ricarte Soto Law”

• Have a National Cancer Law in Chile

• Salud Con Datos GIST Registry Project
ACTIONS

Ricarte Soto Law

Collaborative work:

Patient Advocate & GIST Specialist Team

“Impact of GIST and its treatment in Chile”

Authors: Jorge Madrid Arenas, President Chilean Society of Medical Oncology, Piga Fernandez Kaempffer, President Fundación Chile, Marcelo Garrido Salvo, Gastrointestinal Medical Oncologist.

Health using real world data from the LRG Registry

Presented at:

• Ministry of Health
• Congress Health Comissions
ACTIONS

Ricarte Soto Law

Patient Advocate Experience


Presenting RW data and scientific evidence of treatments to:

• Ministry of Health
• Congress Health Comissions
• Senators
• Deputies
ACTIONS
Ricarte Soto Law
Patient Advocate Experience
Ricarte Soto Law

GIST Specialist Experience

• Dr. Marcelo Garrido, oncologist, Assistant Professor and medical staff of the Red Salud UC-Christus and P. Catholic University of Chile.

• Participation in the advisory boards at the Chilean Ministry of Health to develop treatment protocols and guidelines for GIST.
CÁNCER GASTROINTESTINAL Y GIST:
Un fuerte desafío para las políticas nacionales

Solo en 2012, en Chile se diagnosticaron 2,134 nuevos casos de cáncer y hubo 1,196 muertes por esta enfermedad. En este sentido, es necesario priorizar para las políticas de salud aquellas acciones que no sólo contribuyan a mejorar la calidad de vida, sino que también se hagan de manera efectiva.

Alianza de médicos y pacientes busca entregar propuestas para un manejo adecuado de estas enfermedades.

La Fundación GIST Chile busca dar respuesta a las necesidades de los pacientes y sus familias a través de la creación de una red de asociaciones que trabajan en conjunto para mejorar la calidad de vida de las personas afectadas por esta enfermedad.
OUTCOME
Ricarte Soto Law

PROTOCOLO 2019
Vigencia a partir del 1 de julio de 2019

Tratamiento con Imatinib o Sunitinib en personas con Tumores del estroma gastrointestinal no resecables o metastásicos

Para el Otorgamiento de las Prestaciones que cuentan con el Sistema de Protección Financiera para Diagnósticos y Tratamientos de Alto Costo. Ley 20.850

Subsecretaría de Salud Pública - División de Planificación Sanitaria
Departamento Evaluación de Tecnologías Sanitarias y Salud Basada en Evidencia
GOAL:
National Cancer Law

Alliance: Politicians - Social Society

- Patients and Caregivers
- Advocates
- Health Professionals
- Scientific Societies
- Journalists
ACTIONS:
Advocacy
ACTIONS

National Cancer Law

National Cancer Plan

vs

National Cancer Law
ACTIONS:
March to Create Awareness
OUTCOME: National Cancer Law
President Piñera signed the Plan and the Law
GOAL: NATIONAL CANCER REGISTRY

PRELIMINARY STAGE:
Incorporation of Rare Tumors Registries: GISTs and NETs

Supported by the creation of a National Cancer Law as the result of a collaborative effort of politicians, researchers, academia and patient organizations--setting a way for improvement and development of current health policies.
OUTCOME GIST REGISTRY

COLLABORATIVE PROJECT:
• P. Catholic University
• STORM
• Fundación GIST Chile

Poster presented at SLAGO 2019
April 5, 2019
OUTCOME
GIST Diagnosis and Treatment

With Genomic Analysis performed in addition to immunohistochemical staining and microscopy examinations, the medical team can better identify cases that are red flags and need special medical attention. These results are being registered in the Chilean GIST Registry to determine local mutation frequency of GISTs.
World Health Organization (WHO) - @WHO - 6 abr.

"Health is a human right. No one should get sick and die just because they are poor, or because they cannot access the health services they need." – @DrTedros

Support #HealthForAll | who.int/petition
Thank you!

Questions?

pfernandez@gistchile.cl
pfernandez@liferaftgroup.org

matiasm.m@outlook.com