



Day by Day Adherence Program Support and Orientation Project for MPN patients

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The Max Foundation

Our **mission** is to increase global access to treatment, care, and support for people living with cancer

Our **vision** is a world where all people facing cancer live with dignity and hope

Background

2013

- ❖ Day by Day program started as an initiative to **give orientation and support** to patients facing chronic diseases like CML.
- ❖ This program helped many patients and due to its good results and the needs to help people with other kind of chronic diagnosis it was expanded.
- ❖ Day by Day program started to include **Myelofibrosis** and **Polycythemia Vera** in Chile.

2015

- ❖ In Chile people do not know much about MPNs diseases. Patients face this kind of diagnosis **do not have much information** about this and the available treatments for them and in some cases they don't know where they can find orientation.
- ❖ July 1st, 2019 → **"Ley Ricarte Soto"** started to cover the diagnosis and treatment with Ruxolitinib for MF

Goals

To give coaching in treatment adherence and treatment follow-up

To orient patients about MPNs and their treatments

To provide patients and their caregivers with emotional support

To provide information to patients about the Myelofibrosis in "Ley Ricarte Soto"



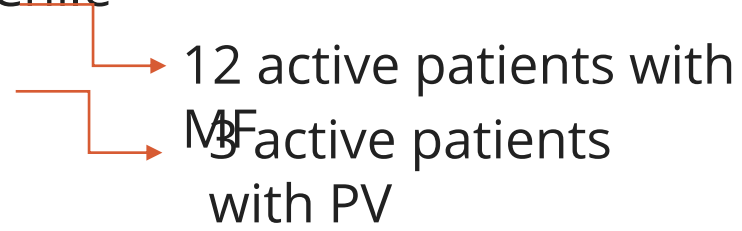
To provide updates on current treatments for MPNs

To provide educational materials to patients

Methodology



Patients from Chile



- ❖ Contact patients through **telephone calls** Information and orientation about their disease and the available treatments; Emotional support.
- ❖ Organization of **patients meetings** Share experiences and learn together
- ❖ **Whatsapp chat group** Always stay connected, they can talk about their needs and worries; Sending of news and updated information about MPNs.

Methodology



- ❖ Sending **educational materials** to the patients → More access to the available information about MPNs.
- ❖ **Patient Navigation** → Help from an external consultant to navigate the health system with patients and thus find ways of accessing treatments for those who required it in that moment.
- ❖ Patients are **informed** and **enrolled** in the program through the help of their **treating physician** → Physicians also collaborate by participating and giving educational presentations at patient meetings.

Our Day by Day Program



Results

Creation of a patient network

Feeling of inclusion for each patient and their families, they are grateful

Physicians are happy with the program, patients now are more proactive and informed

Collaboration with laboratories in the work of raising awareness about MF



“Ley Ricarte Soto”

(Ley n°20.850)

June
2015

- ❖ “**Ley Ricarte Soto**” (Ministry of Health) Creation of a financial protection system for **high-cost diagnoses and treatments** for specific health conditions (oncological, immunological and rare or infrequent diseases).
- ❖ Provides **financial protection** to all users of the health pension systems, regardless of their socioeconomic status.

July
2019

- ❖ Incorporation of the coverage for the **diagnosis and treatment** with **Ruxolitinib** for patients diagnosed with Primary and Secondary **Myelofibrosis** to other myeloproliferative neoplasms Philadelphia negative.
- ❖ In total it covers 27 diseases
- ❖ Currently there is **no coverage** in Chile from the health system for the treatment of **Polycythemia Vera or**

MPN patients treatments in Day by Day

Myelofibrosis (MF)



Ruxolitinib (Jakavi): 5 patients



Hydroxycarbamide: 4 patients



Without treatment: 2 patients



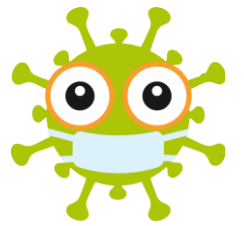
Others: 1 patient

Polycythemia Vera (PV) patients



Ruxolitinib (Jakavi): 3

Covid-19



- ❖ During this year we have faced a **global pandemic** that has had important impacts in various areas of life.
- ❖ Health Area → Patients of the program that **needed to start** their treatment for MF with Jakavi during this period, it **took some months** to them to **receive the medication** and some of them are **still waiting** for that.
- ❖ But the patients who were **already taking** this treatment had **no problem** receiving their medication on time.
- ❖ So we could reflect and analyze whether this **delay in the approval** of patients in the law is due to the **context of the pandemic** or if the **law is being implemented** in the country.



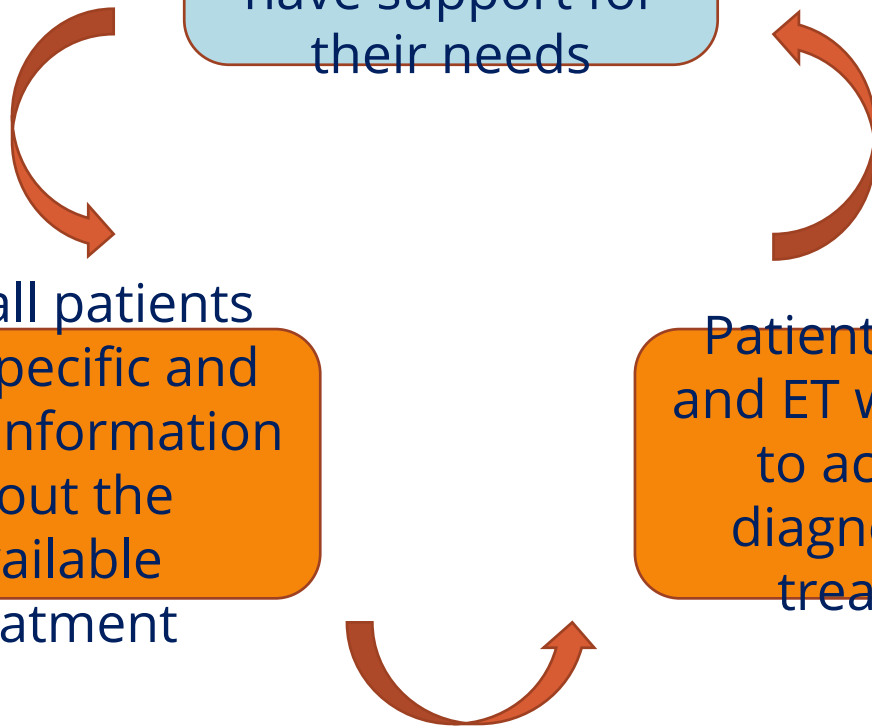
Challenges



Reaching all MPN patients in Chile so that they can have support for their needs

Help all patients with specific and useful information about the available treatment

Patients with PV and ET will be able to access to diagnosis and treatment





THANK YOU!

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