

- Title: Impact of COVID19 on the access to healthcare services for children with Down Syndrome
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- Introduction: There are approximately 8,800 people with Down Syndrome in Peru, most of them have comorbidities that increase their susceptibility to develop severe acute lung disease due to the COVID19. According to the Peruvian Clinical Guideline for the Management of Down Syndrome, there is a standard medical care for the affected pediatric population. However, the COVID19 pandemic limited the access to medical services in this population, both for regular visits due to the condition and urgent care due to COVID19. Knowing the impact of COVID19 on the health care of people with Down Syndrome will help to identify the magnitude and characteristics of the healthcare services in this community.

This project is a cross sectional study that will interview parents of children younger than 12 years old about their access to healthcare services before and during the pandemic. With the collaboration of the Down Syndrome Peruvian Society, we will enroll the participants. We will use a virtual or telephone survey.

- Vision: As genomics advances towards personalized medicine, we need to improve the healthcare of patients with already known genetic conditions. In this way, this is

the first study of many to characterize the healthcare in patients with rare conditions and optimize medical care with the use of new technologies.

- Aims:

General Aim: To know the impact of the COVID19 pandemic on the access to healthcare services for children with Down Syndrome in Peru.

Specific Aims:

1. To know the demographic and clinical profile of people with Down Syndrome
2. To know the access to healthcare services for children with Down Syndrome before the COVID19 pandemic
3. To know the access to healthcare services for children with Down Syndrome during the COVID19 pandemic and compare it to the access before the pandemic.

- Impact:

Our study is the first one in Latin America to address the gap in healthcare access that exists for vulnerable populations such as those with Down Syndrome. Thus, it will increase the awareness about the importance of healthcare services about secondary and tertiary prevention for patients with Down syndrome and other genetic diseases. Furthermore, it will strengthen the collaboration among the Down Syndrome community, the Peruvian Society of Down Syndrome, and the healthcare professionals. Therefore, this study will be a resource to address the existing inequalities and advocate for improvements in the healthcare of children with rare

diseases, including new diagnostic methods and novel treatments.

- Executive Plan: Project plan outlining goals and activities in quarterly format

May – July 2021: Project writing

August- October 2021: IRB review, pilot study

November 2021- January 2022: Data collection

February – April 2022: Data analysis, final report, and publication.

- G2MC Partners: Tania C Vasquez Loarte (young investigator/ USA)
- Other Organizations: Universidad Nacional Peruana Cayetano Heredia, Sociedad Peruana de Síndrome de Down.
- Future funding:
- Budget with brief

| Description                      | Price (USD) |
|----------------------------------|-------------|
| IRB review and other permissions | 300.00      |
| Onsite research assistant        | 6000.00     |
| Online survey                    | 200.00      |
| Total                            | 6500.00     |

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