

To consult the online version, [click here](#)



What is new?

IRDiRC HIGHLIGHTS

IRDiRC Conference & RE(ACT) Congress

13-15 JANUARY 2021



IRDiRC is glad to organise the **4th IRDiRC Conference** in a joint online event with the **RE(ACT) Congress** that will take place on 13-15 January 2021. It aims to bring together **scientific leaders, patients, and policy makers** to advance research on rare diseases.

To obtain your discount register [here](#) before **31st of December**.

Note that **in compensation to attendees who registered before the announcement of the event being moved online, 3 free extra accesses will be granted** to them to invite guests.

The program is available [here](#).



Registration

Leadership changes

- **Dr. Philip John Brooks**, Program Director at the Office of Rare Diseases Research, National Center for Advancing Translational Sciences, National Institutes of Health, is the new elected Chair of the **Interdisciplinary Scientific Committee**.

- **Mrs. Samantha Parker**, Chief Patient Access Office at Lysogene, is the new elected Vice Chair of the [**Companies Constituent Committee**](#).

IRDiRC Publications

The paper [**Barriers and Considerations for Diagnosing Rare Diseases in Indigenous Populations**](#) has been published in [**Frontiers**](#). This article was written on behalf of the [**IRDiRC Indigenous Population Task Force**](#).

[Read](#)

Task Forces

Two new task forces will start in Q1 of 2021. **A call will be opened as soon as they start.**

- [**Integrating New Technologies for the Diagnosis of Rare Disease**](#)

Identification of new technologies in development or in experimental use which are likely to increase the diagnostic rate for patients with rare diseases, and to identify opportunities to enable the safe, widespread clinical adoption of the most elective technologies in a meaningful timeline.

- [**Shared Molecular Etiologies**](#)

Expanding patient access to rare disease clinical trials by focusing on shared molecular etiologies underlying multiple rare diseases.

[More Information](#)

IRDiRC IN EVENTS

IRDiRC held the following meetings:

- 16 July 2020: **19th IRDiRC Consortium Assembly meeting**
- 29 September 2020: **18th IRDiRC Diagnostics Scientific Committee meeting**
- 1-2 October 2020: **20th IRDiRC Consortium Assembly meeting**

To see the available reports and to get more information press the button below.

[More Information](#)

IRDiRC has been presented in the following events:

- 13 October 2020: IRDiRC's [**Orphan Drug Development Guidebook**](#) (ODDG) was presented at the **European Commission**
 - 24-25 October 2020: **China Conference on Rare Diseases**
 - 2-5 November 2020: **World Orphan Drug Congress**
-

You received this email because you are registered with INSERM - DR6 Paris
To modify your preferences OR unsubscribe from this list [click here](#)