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](#).

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 Constituency 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*.

**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.

**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.

**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