

***Together for a Bright Future***  
**Registration Notice for**  
**2025 International Rare Disease Conference of China**

In the context of globalization, rare diseases have become a major challenge that urgently requires collective action from global health systems. To promote international cooperation in the prevention, control, and research of rare diseases, China Alliance for Rare Diseases(CHARD), the Office of National Collaboration Network for the Diagnosis and Treatment of Rare Diseases, the International Rare Diseases Research Consortium (IRDiRC), the Bill & Melinda Gates Foundation, and the Chinese Red Cross Foundation have worked together with multiple domestic and international medical institutions and academic organizations to organize the *2025 International Rare Disease Conference of China* in Haikou, Hainan Province, China, scheduled for **23-25 May, 2025**.

With the theme of “Together for a Bright Future”, this conference aims to establish a new highland for international cooperation in rare diseases and facilitate the deep integration of resources and elements. This event consists of multiple forums, the China International Rare Diseases Medical Devices and Innovations Exhibition, the China Rare Diseases Research Innovation Competition, and over ten other sections. Experts and scholars from government, medical, pharmaceutical, and research fields both domestically and internationally will share advanced practices in their respective areas, engage in in-depth exchanges on new knowledge, policies, and practices in the field of rare diseases, and promote the joint creation and sharing of global rare diseases ecosystem achievements, contributing to the cause of human health.

➤ **Time**

23-25 May, 2025

The Opening ceremony and the main forum is scheduled on the morning of 24 May.

➤ **Venue**

The Marriott hotel at Haikou city, Hainan Province, China

➤ **Draft Agenda**

**23 May**

13:30-22:00      Registration

19:00-21:00      Academic Salon of "Force of Innovation and Quality" Rare Disease Research

**24 May**

08:30-12:00      Opening Ceremony and Main Forum

12:20-14:00      Lunch/China International Rare Disease Medical Device Innovation Exhibition

The Launch of Xinyang Innovative Drug and Device

14:00-18:00      Special Forum on Lysosomal Storage Disorders (LSDs)  
Special Forum on Myasthenia Gravis (MG)

14:00-15:40      Sub-forum 1

Global policies and strategies of rare disease security

Sub-forum 2

Diagnosis and treatment system and pathways of rare diseases

Sub-forum 3

Market access and evidence-based decision-making for rare disease drugs

Sub-forum 4

The latest progress in rare disease diagnostic technology

15:40-16:10      China International Rare Disease Medical Device Innovation Exhibition

Seminar

16:20-18:00      Sub-forum 5

Global status and trends in the development of new drugs for rare diseases

Sub-forum 6

Optimizing the care and rehabilitation services for patients with rare diseases

Sub-forum 7

International experience in health technology assessment of rare disease drugs

Sub-forum 8

Global innovative therapies and precision diagnosis and treatment of rare diseases

18:30-20:30 "Sea and Grass" Concert

The Launch of Xinyang Innovative Drug and Device

## **25 May**

08:00-12:00 Special Forum on Hereditary Angioedema (HAE)

Special Forum on Complement Inhibitors

08:00-09:40 Sub-forum 9

Special Session on Rare Hematological Diseases

Sub-forum 10

Special Session on Transthyretin Amyloidosis (ATTR)

Sub-forum 11

Special Session on Amyotrophic Lateral Sclerosis (ALS)

Symposium

Sub-forum 12

Special Session on Duchenne/Becker Muscular Dystrophy (DMD/BMD)

09:40-10:10 China International Rare Disease Medical Device Innovation Exhibition

Seminar

10:20-12:00 Sub-forum 13

Special Session on Short Bowel Syndrome (SBS)

Sub-forum 14

Special Session on Multiple Sclerosis (MS) and Neuromyelitis

Optica Spectrum Disorder (NMOSD)

Sub-forum 15

Special Session on Neurofibromatosis (NF)  
Sub-forum 16  
Special Session on Paroxysmal Nocturnal Hemoglobinuria (PNH)  
12:00-14:00 Lunch/China International Rare Disease Medical Device  
Innovation Exhibition  
The Launch of Xinyang Innovative Drug and Device

➤ Conference Format

The conference will adopt a **hybrid** format combining both online and offline pathways, with select sessions being broadcast live across multiple platforms. The live streaming platform will be the *2025 International Rare Disease Conference of China* section on the WeChat and Baidu Mini Programs of CHARD. Some sessions will also be live-streamed on the WeChat Video Account of CHARD

➤ Topics

The conference will encompass various topics including policy and institutional reform for rare diseases, the construction of diagnosis and treatment systems, research innovation and conversion, health technology assessment, research on specialized medical nutrition, patient care and rehabilitation management, among others. Additionally, there will be multiple thematic forums focused on specific rare diseases and disciplines, such as neurology, hematology, rare tumors, lysosomal storage disorders, myasthenia gravis, hereditary angioedema, transthyretin amyloidosis, etc. The conference invites experts and scholars from both China and abroad to jointly formulate a global strategy for rare disease prevention and control, and to promote multilateral cooperation and knowledge sharing.

➤ Participants

The conference is open to individuals from all over the world working in the field of rare diseases. It plans to invite leaders from relevant domestic and international departments, policymakers,

representatives from international rare disease organizations, managers of internationally renowned medical institutions, leading experts and key personnel in rare disease diagnosis and treatment, managers and medical staff from renowned hospitals, which are the members of the National Collaboration Network for the Diagnosis and Treatment of Rare Diseases, researchers from scientific research institutes, representatives from patient organizations, and representatives from leading pharmaceutical and biotechnology companies.

➤ Accommodation, Transportation Arrangements, and Fees

The conference will provide working lunches for offline participants. Participants are responsible for their own accommodation and transportation arrangements.

➤ Registration

(1) Conference Registration

Please complete your registration through the conference's official website: <https://www.chard.org.cn/en/conference/detail/1240#registration>. (Please click this link by your computer)

Note:

1. Both online viewers and offline participants must register.
2. Offline participants will be provided with working lunches, tea breaks, and conference-related materials on the 24th and 25th, May.

(2) Registration Fee

For onsite participants:

Early Registration : \$420 Before March 15, 2025

Standard Registration: \$520 Before May 25, 2025

Note:

1. Offline payment is not available and no refund will be processed after 1:30 pm, May 23, 2025.

2. Please fill in the invoice information form carefully during your registration, and an electronic invoice will be issued and sent to your email address after the conference.

➤ Instructions for Exhibition Participation

During the conference, the “China International Rare Disease Medical Device and Pharmaceutical Innovation Exhibition” will be held to facilitate the connection and cooperation between research institutions, pharmaceutical companies, medical institutions, and patient groups, as well as to gain insights into the latest research and development progress and patient needs in the field of rare diseases. The exhibition is open to all rare disease innovation enterprises, research institutions, and medical institutions. The registration deadline for the Exhibition is April 30, 2025. Please contact us by email or phone for exhibition registration. Contact information for exhibition participation is attached below.

➤ Check-in Arrangement for the Conference

At the Check-in desk arranged in the conference hall, please show your check-in code to complete the conference check-in and get your conference materials.

➤ Contact Us

IRDCC Organizing Committee

Tel: 0086-1065699659

Email: [IRDCC@chard.org.cn](mailto:IRDCC@chard.org.cn)