



12th Annual ICORD Conference 6th China Rare Disease Summit

第十二届国际罕见病与孤儿药大会暨第六届中国罕见病高峰论坛

September 7th~10th, 2017 | Beijing China

CONFERENCE REPORT 总结报告

Rare Diseases, Global Challenges and China's Role
罕见病的全球挑战与中国角色





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1. Executive Summary

The 12th ICORD Annual Conference/6th China Rare Diseases Summit was jointly organized by ICORD, CORD (Chinese Organization for Rare Disorders) and PUMCH (Peking Medical Union College Hospital). It was successfully held in Beijing on 7-10 September, 2017. With 700+ attendees from 20+ countries around the world, this was the biggest rare disease conference ever held in China. Over 100 distinguished speakers presented at 20 sessions. The conference also attracted broad media interests, with 49 reporters providing coverages at and after the conference. There have been overwhelmingly positive feedbacks during and after the conference:

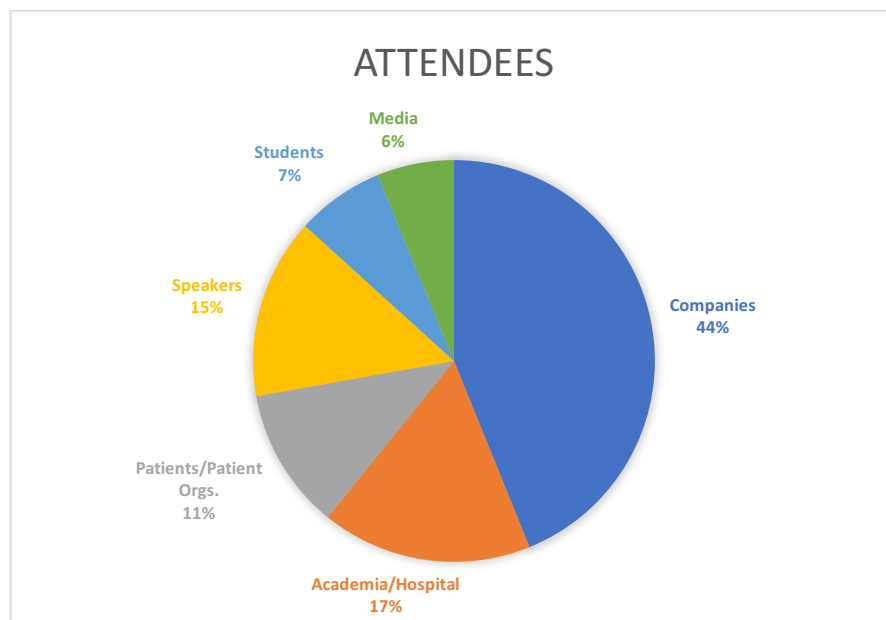
- This is the most well-thought-out RD conference I have ever been
- The speaker assistants are very helpful.
- It's encouraging to see senior Chinese government officials speaking and supporting the conference, kudos for the two Chinese local organizers.
- The attendee representation covers nearly all rare disease spectrum, a great job to the organizers for promoting the conference.
- The conference is jam-packed with world class speakers with high caliber content
- Interesting and engaging audience participation and discussions





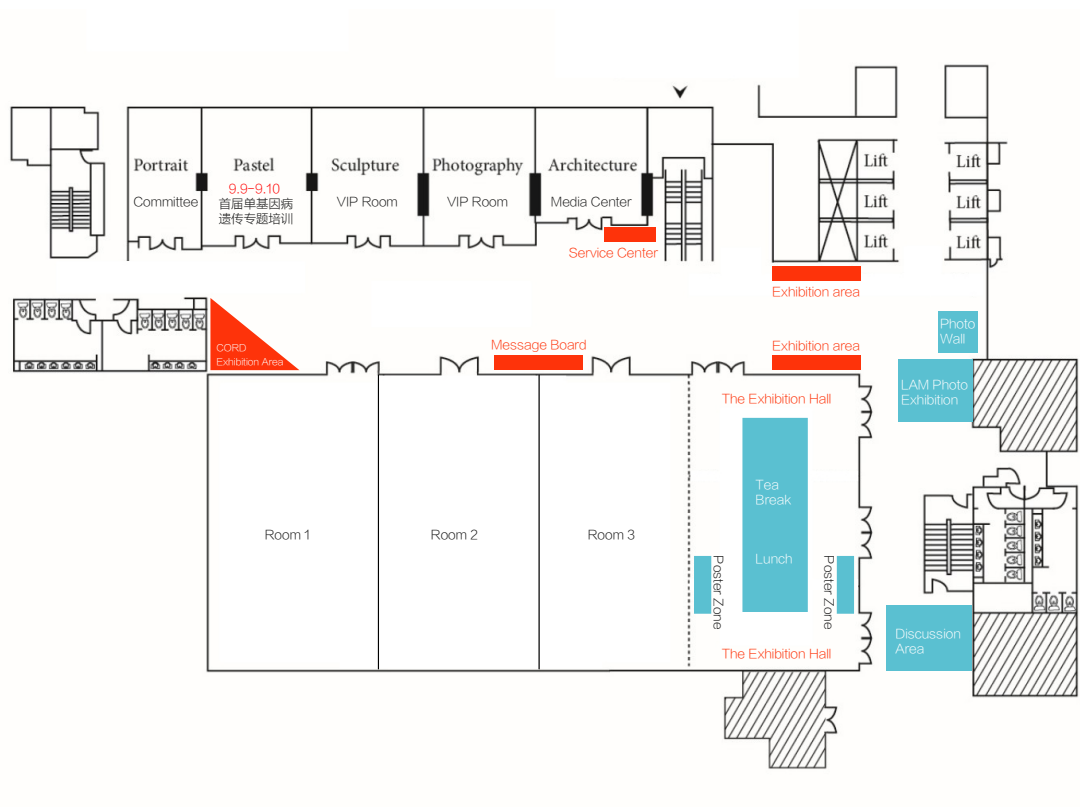
2. Attendees Overview

The initial target for the number of attendees was 500-600, with PUMCH as the local co-organizer, and the significant interests from the media, total attendees reached over 700. The breakdown of the attendees in different categories are listed below.



3. Venue

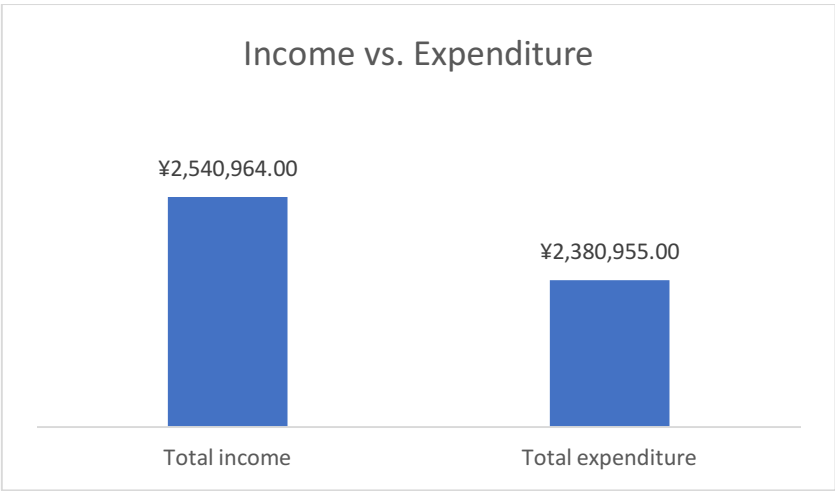
The conference was held at JW Marriott Hotel Beijing, a five-star hotel located in CBD of city of Beijing, with quality accommodations. The hotel is easily accessible through public transportation. Conference rooms, exhibition area, poster area and dining hall are all well-organized. Service Centers were set up throughout the conference for attendees to seek information or schedule meetings.



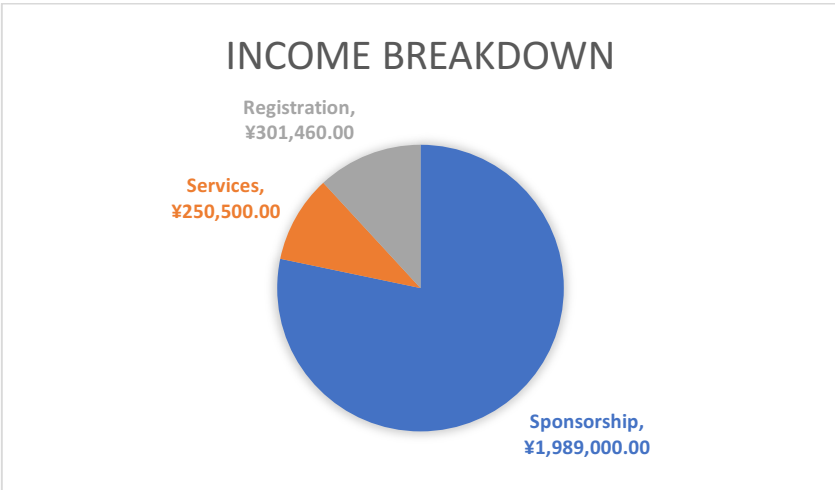
4. Finances

In order to draw high ranking government officials and top medical experts, conference venue and other standards must be up to certain standards (a 5-star hotel is a must). This is rather cultural. Venues in 5-star hotels and the services they provide are expensive in cities like Beijing. CORD, with the crucial contribution from PUMCH, raised to the challenges and successfully secured the necessary funds. Using creative sponsorship packages and attractive service offerings, not only did CORD make ends meet, but managed a small surplus.

■ Total Income vs Expenditure:



■ Income Breakdown by Sources:



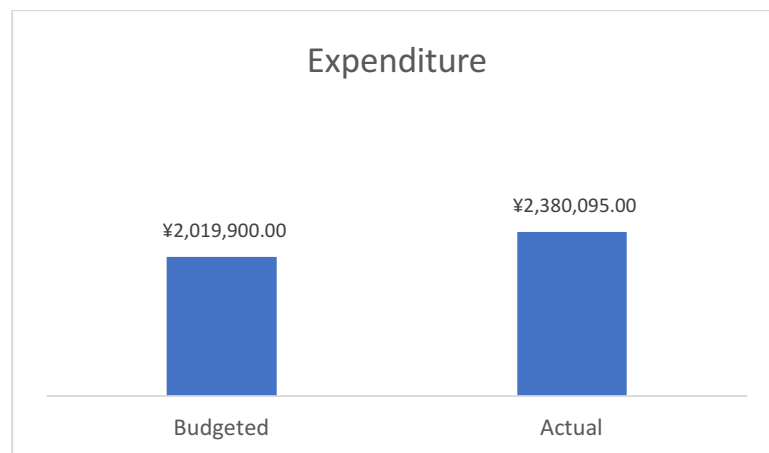
■ Registration Fee Schedules:

	Early Bird(RMB)	Regular Fee (RMB)	On-Site (RMB)
International Attendee	1200	1500	1800
Domestic Company Attendee	900	1200	1500
Domestic Academic Institute/Hospital	600	900	1200
Patient / Family	200	250	300
Student	100	150	200

■ Total Expenditures: Budgeted vs. Actual

Total expenditures exceeded the budget due to the following factors:

- The location is in Beijing instead of Shanghai, as was quoted in the original budget.
- Hotel contract was finalized late due to the change of venue.
- Total attendees increased from the initially anticipated 500+ to 700+.
- The conference standard was raised as a result of the endorsement of the high level government officials.



■ Expenditures Breakdown: Budgeted vs. Actual

Category	Budgeted (RMB)	Actual (RMB)
Venue	737400.00	720557.84
Speakers	195000.00	171553.61
Conference Room Facilities	68000.00	262183.00
Materials	136000.00	165742.69
Conference Services	145500.00	253668.13
Human Resources & Management	624000.00	624000.00
Program Committee	64000.00	32389.99
Other (Taxes)	50000.00	150000.00
总计	2019900.00	2380095.26

5. Sponsorship Overview

To meet the daunting challenges of raising the funds, CORD creatively created diverse sponsorship programs that appealed to different sponsor types, sponsors with different budgets and resources. At times, we had to modify the programs to tailor to specific requests from a potential sponsor who was interested but had difficulties finding a package that suited its unique needs.

See Appendix I for the Sponsorship Prospectus.

1) Sponsorship Packages:

		Diamond	Platinum	Gold			Silver	
	Sponsor Level (RMB)	500K	300K	250K	200K	150K	100K	50K
1	Opening Ceremony Speech	Y	N	N	N	N	N	N
2	Free satellite seminar (1 session)	Y	N	N	N	N	N	N
3	Closing Ceremony Speech	N	Y	N	N	N	N	N
4	Media interview	Y	Y	Y	N	N	N	N
5	Display at the Poster	N	N	Y	N	N	N	N
6	Recommend Speaker (subject to review and approval by the hosts)	Y (2)	Y(1)	Y(1)	Y(1)	Y(1)	N	N
7	Recommend Session Chair/speaker (subject to review and approval by the hosts)	N	N	N	N	N	N	N
8	Coffee break, Lunch	N	N	N	N	N	Y	N
9	Ad pages in program book	Y	Y	Y	Y	Y	Y	N
10	Exhibit	Y	Y	Y	Y	Y	N	N
11	Acknowledgement on video display	Y	Y	Y	Y	Y	Y	Y
12	LOGO display on website	Y	Y	Y	Y	Y	Y	Y
13	Complimentary registration	10	8	6	4	2	2	1
14	Certificate of Sponsorship	Y	Y	Y	Y	Y	Y	Y
15	Ad on the displaying board	Y	Y	Y	Y	Y	Y	Y
16	Pull-up Banner	Y	Y	Y	Y	Y	Y	Y
17	Program Book LOGO Display	Y	Y	Y	Y	Y	Y	Y

2) Special Sponsorship Opportunities:

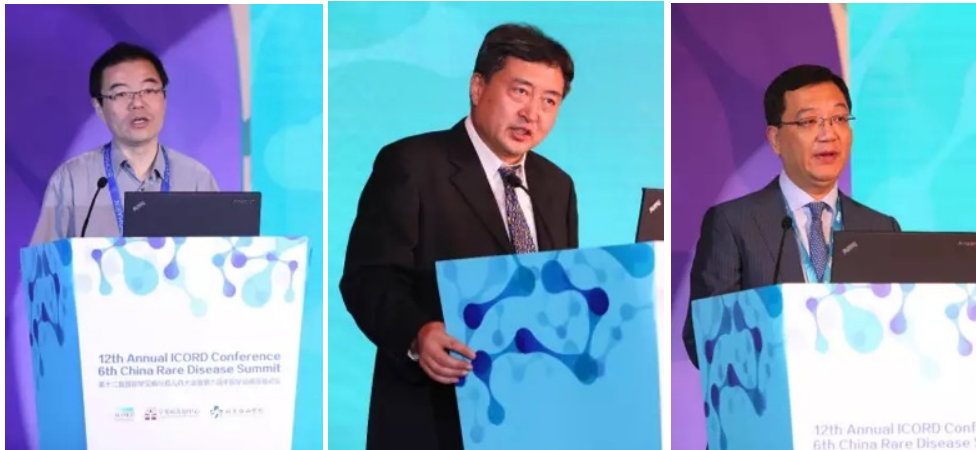
	Acknowledge at welcome dinner	Meeting Bag	Badge	Sponsor for Gifts
Sponsor level (RMB)	400K/sponsor	100K/sponsor	60K/sponsor	50K/sponsor
1	4 Guest seats for welcome dinner	LOGO display on website	LOGO display on website	LOGO display on website
2	Speech at dinner	Certificate of sponsorship	Certificate of sponsorship	Certificate of sponsorship
3	Name for the dinner night	LOGO display	X	Acknowledge at session PPT
4	Logo display on dinner table	X	X	Present gifts at closing ceremony
5	Introduction	X	X	Note: Non-company products
6	Distribute gifts with approval from program committee	X	X	2 sponsors available
7	Certificate of Sponsorship	Note: 2 sponsors available	X	X

3) Exhibition and Services

	Exhibit (10 units)	Exhibit (5 units)	Satellite Seminar (4 sessions)	VIP Room	Ad (color page) in Program				Photo print
					Page 2	Page 3	Inside	Pull-out page	
Sponsor level (RMB)	20K/each	60K/each	40K/each	3K/room/hour	20K	20K	10K/pg	25K/pg	10K
	2*2 sq.meter	3*3 sq.meter	Duration 1 hour	Sept 8: 13:00-21:00 Sept 9: 10:00-21:00 Sept 10: 10:00-12:00	1 page	1page	No limit	No limit	LOGO Display
	10 units	5 units	Room and equipment provided	-	A4	A4	A4	A4*2	Sept 8-10
	X	X	Sponsor organize the session	X	X	X	X	X	X
	X	X	Included in program	X	X	X	X	X	X
	X	X	Pre-meeting Announcement	X	X	X	X	X	X
	X	X	Sept 9, lunch time	X	X	X	X	X	X

6. Conference Programme

The three-day conference was jam-packed with pre-conference workshops; multi-track parallel sessions, and lunch-time satellite symposiums.

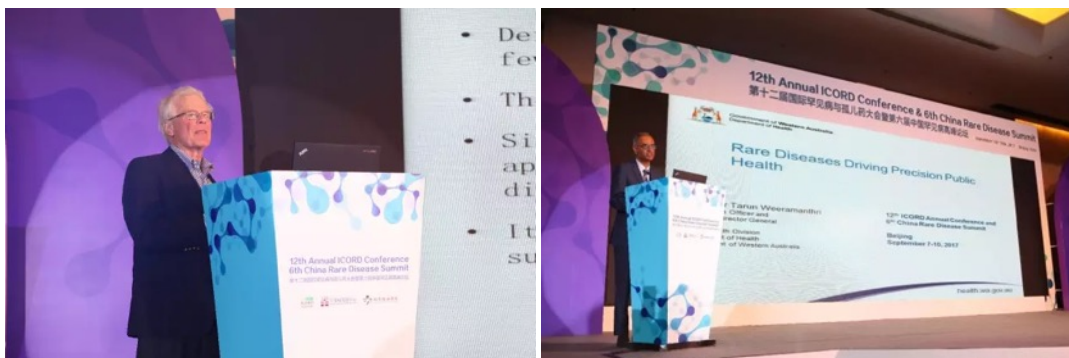


The Opening Ceremony of the conference was made significant with the attendance of several high-level government officials. Congratulatory remarks from the two national level government officials: Baoguo Tian, Deputy Director-General, Chinese Department of Sciences and Technologies and Yanhong Guo, Deputy Director-General of the Bureau of Medical Administration, National Health and Family Planning Commission opened the conference on a high note. The three co-organizers represented by Prof. Shuyang Zhang, Vice President, PUMCH; Manuel Posada, President, ICORD; and Kevin Rufang Huang, President, CORD gave warm welcome to all the distinguished guests, speakers and attendees from around the world.





Key note speakers presented their views on how to address the global challenges of rare diseases from each of their unique perspectives. Kevin Rufang Huang; who spoke from his own personal encounter growing up as a rare disease patient in China about the importance of involving patients in finding resolutions for rare diseases. Dr. Harvey Lodish, a world-renowned biotechnology serial entrepreneur, talked about, from his own aspiring personal story, how academic entrepreneurs can use technologies to build companies to treat rare diseases. Rare diseases are not diseases of a few people, it's a public health issue, Dr. Tarun Weeramanthri shared with us how West Australia government tackles rare disease challenges to drive precision public health. Although a late starter, China is catching up fast and furious, Professor Shuyang Zhang gave an update on research and intervention on rare diseases in China.



The following four half-days were packed with interesting sessions delivered by experts in their respective fields, with attendees actively participating interactive discussions and exchanges. The wide spectrum of attendees made the cross pollination of thoughts and ideas possible and meaningful; and planted seeds for future collaboration.



7. Marketing

Multiple channels were explored to market the ICORD 2017 both in China and internationally. Traditional media as well as internet were used to disseminate the information and promote the conference. Conference website was quickly assembled with up-to-date information about the conference programme, invited speakers, venue, registration etc. A Wechat public account was created for the conference leveraging the ultra-popular Chinese social media application. Those who are interested can register directly on the conference website or through Wechat. Email blasts were sent out periodically with updates on the conference preparation to keep the interests high.

Below are some of the marketing materials used to promote the conference:



8. Partners / Sponsors / Exhibitors

Special thanks to our partners, sponsors, and exhibitors for their support. Without them, the conference would not have been possible. Due to variations on the sponsored amount within the same level of sponsorship package, the exact amount from each sponsor is not disclosed here in this report as agreed upon with the sponsors.

1) Partners:

全球合作伙伴



合作伙伴



2) Sponsors/Exhibitors:

Sponsors / Exhibitors	Sponsor Level
Shire	Diamond
Amgen	Gold
CSL Behring	Gold
Kingmed Diagnostics	Gold
Veritas Genetics Inc	Gold
NIKYANY	Gold
China Primary Health Care Foundation	Gold
BGI Genomics Co	Gold
NextCODE Health	Silver
Alexion	Silver
Astrazeneca	Silver
Biomarin	Silver
CSPC	Silver
GeneDock.com	Silver
One Foundation	Silver
Pfizer	Silver
Illumina	Exhibitor
GrandOmics	Exhibitor
More Health	Exhibitor
Loxam Vascular	Exhibitor
Haplox	Exhibitor
Unite Gen	Exhibitor
Amcare Genomics	Exhibitor
Joy Orient	Exhibitor
Wuxi Biologics	Exhibitor
Pumch	Exhibitor
Actelion	Exhibitor
BGI Genomics Co.	Exhibitor

3) Media:

合作媒体

