IAS-ILF/CIPHER THEMATIC ROUNDTABLE ON PAEDIATRIC HIV

Removing barriers and seizing opportunities in paediatric HIV

19 July 2014
AIDS 2014, Melbourne, Australia

Evaluation report
Introduction

Following the success of the IAS-ILF Industry Roundtable on Paediatric Antiretrovirals (ARVs), held in Geneva, Switzerland, in November 2013, the International AIDS Society-Industry Liaison Forum (IAS-ILF) and the Collaborative Initiative for Paediatric HIV Education and Research (CIPHER) teamed up to organize a follow-up roundtable on paediatric HIV. This closed meeting was held in conjunction with AIDS 2014 (20-25 July 2014, Melbourne, Australia). It was aimed at widening the scope of the discussion from mainly ARV manufacturers and international organizations to include investigators from the largest paediatric HIV cohorts worldwide (through the CIPHER Cohort Collaboration), as well as representatives of normative and regulatory agencies.

The IAS-ILF/CIPHER Thematic Roundtable on Paediatric HIV was co-chaired by Lynne Mofenson (US National Institutes of Health, USA) and Shaffiq Essajee (CHAI, USA). It was aimed at bringing cohorts and industry together for an informal discussion and knowledge sharing between the various stakeholders with the hope of extending collaboration between cohorts’ investigators and industry. The agenda is available in Appendix A.

Attendance

Fifty-one people participated, and most (61%) were female. Twenty-four percent represented the cohorts, 22% represented industry, and 54% represented other organizations (including the IAS, see Figure 1).

Feedback from participants

Participants were invited by email to fill in an online survey (see Appendix B). Thirteen surveys were completed (a 25% response rate). The majority of respondents were based in the USA (46%) with the rest coming from Switzerland (15%), Spain (15%), Papua New Guinea (8%) and Thailand (15%). The majority of respondents (31%) were affiliated with hospitals or academia and non-governmental organizations; 23% were affiliated with governments (see Figure 1).

Participants were asked which conferences or meetings they usually attend (respondents were asked to select all options that applied). Seventy-seven percent said that they usually attend the International AIDS Conference, 62% said that they attend the Conference on Retroviruses and Opportunistic Infections (CROI), and 54% said that they attend the IAS Conference on HIV Pathogenesis, Treatment and Prevention. Seven respondents (54%) said that they usually attend the International Workshop on HIV Paediatrics (organized by Virology Education).
When asked about the main reasons for attending the roundtable (respondents were asked to select all options that applied), 85% said that they attended to discuss challenges and come up with solutions, while 23% said that they attended to make new contacts. Fifteen percent of the respondents said they attended to learn more about paediatric HIV; an equal portion (15%) attended to present data on paediatric HIV. The majority of respondents (69%) gained the opportunity for collaboration, and 54% gained the opportunity to share their ideas. Thirty-nine percent of the respondents gained new contacts, and 23% gained new information on paediatric HIV. When asked if they would follow up on the new contacts made, 69% of respondents said that they would, while 31% of the respondents answered with “maybe”.

Participants were asked to rate the various parts of the roundtable (presentations and roundtable discussion). Sixty-five percent of respondents rated the various parts as good, 23% as excellent, and 8% as fair. Regarding the organization of the roundtable, 69% of respondents rated it as good and 25% as excellent. For future improvements, 62% of respondents suggested allowing more time for discussions, and 46% suggested providing more information in advance (before the meeting). Thirty-nine percent of respondents suggested narrowing the scope of the topics discussed and inviting more industry participants.

Participants were asked to suggest subjects for future roundtables. Only two suggestions were made. One respondent suggested having an “industry proposed action plan”, and the other suggested a “focus on specific molecules (i.e. on specific drugs); either in this [meeting] format or in another”. When asked about whether a major stakeholder was absent from this roundtable, one respondent said that there should be more regulators at these meetings (there were three).

Overall, the roundtable was positively received with respondents making positive comments, as well as taking the opportunity to make a few suggestions. Some comments and suggestions included:
- “The momentum needs to be maintained with six-monthly meetings to enable incremental progress.”
- “[The meeting] should be more practical.”
- “Participants list should be tightened to reflect those likely to participate and who know the field.”
- “Better [scheduling] for the meeting [is needed].”
- “Same ideas are repeated and are too far from actual implementation.”
- “There was no clear action plan with timelines and responsible [persons or organizations].”
### THEMATIC ROUNDTABLE ON PAEDIATRIC HIV

Organized by the International AIDS Society-Industry Liaison Forum (IAS-ILF) and the Collaborative Initiative for Paediatric Education and Research (CIPHER)

Saturday, 19 July 2014, 18:00 – 21:00 AEST (Dinner reception until 22:00 AEST)  
Fig/Pear Room, Mercure Melbourne Treasury Gardens  
13 Spring Street, Melbourne VIC 3000 Australia

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
</tr>
</thead>
</table>
| 18:00 – 18:10 | Welcome and roundtable introduction  
  *Co-Chairs:* Lynne Mofenson (US National Institutes of Health, USA)  
  Shaffiq Essajee (CHAI, USA) |
| 18:10 – 18:25 | Challenges along the paediatric ARV pipeline:  
  *Summary of the IAS-ILF Industry Roundtable on Paediatric ARVs*  
  Shaffiq Essajee (CHAI, USA) |
| 18:25 – 18:45 | CIPHER and Paediatric HIV cohorts collaboration  
  *Marissa Vicari (IAS, Switzerland)*  
  *Annette Sohn (TREAT Asia / amfAR, Thailand)* |
| 18:45 – 18:55 | Knowledge gaps and WHO guidelines  
  *Martina Penazzato (WHO, Switzerland)* |
| 18:55 – 20:50 | Roundtable discussion  
  Removing barriers and seizing opportunities in paediatric HIV  
  What can cohorts do for industry? What can industry do for cohorts?  
  Can collaboration between cohorts and industry tackle some of these challenges?  
  • Developing child-friendly formulations  
  • Recruiting children under 12 years in clinical trials  
  • Gathering information on most appropriate:  
    o Formulations  
    o FDC ratios  
    o Age bands  
    o Weight bands  
  • Providing clinical data (e.g., PK data)  
  • Providing accurate post-marketing surveillance data  
  • Informing paediatric HIV cure research by looking for Mississippi baby-like patients  
  *Facilitator:* Shaffiq Essajee (CHAI, USA) |
| 20:50 – 21:00 | Summary and action points  
  *Co-Chairs:* Lynne Mofenson (US National Institutes of Health, USA)  
  Shaffiq Essajee (CHAI, USA) |
| 21:00 – 22:00 | Dinner reception for additional informal exchanges between participants |
Appendix B: Evaluation form (page 1 of 2)

1. What were the main reasons for attending this meeting? (Please select all that apply.)
   - ☐ To present data on paediatric HIV
   - ☐ To learn more on paediatric HIV
   - ☐ To discuss challenges and come up with solutions
   - ☐ To make new contacts

2. What did you gain from attending this meeting? (Please select all that apply.)
   - ☐ New information on paediatric HIV
   - ☐ Opportunities for collaboration
   - ☐ Opportunities to share ideas
   - ☐ New contacts

3. Will you follow-up on new contacts made at this meeting?
   - Yes: ☐
   - Maybe: ☐
   - No: ☐

4. How would you rate the presentations made?

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and roundtable introduction</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Presentation of the IAS Paediatric Priority (CIPHER)</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Challenges along the paediatric ARV pipeline: Summary from the Industry Roundtable on Paediatric ARVs</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Paediatric HIV cohorts</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Knowledge gaps and WHO guidelines</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Roundtable discussion: Removing barriers and seizing opportunities in paediatric HIV</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Summary and action points</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

5. How would you rate the organization of this meeting?

<table>
<thead>
<tr>
<th></th>
<th>Excellent</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choice of topics</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Choice of contributors</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Choice of attendees</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Format of the session</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Duration of the event</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Date/time of the events</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Direction and time management by co-chairs and moderators</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Overall organization</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

6. How could future thematic roundtables be improved?

   - ☐ Improve general organization
   - ☐ Provide more information in advance
   - ☐ Broden the scope of topics discussed
   - ☐ Narrow the scope of topics discussed
   - ☐ Allow more time for presentations
   - ☐ Reduce time for presentations
   - ☐ Allow more time for discussion
   - ☐ Invde more industry participants
   - ☐ Invite more non-industry participants
Appendix B: Evaluation form (page 2 of 2)

7. What subject(s) would you suggest for future IAS-ILF thematic roundtables?

8. Do you feel any important stakeholder(s) was(were) absent from this meeting? If yes, please let us know which one(s).

9. Do you have any general comments, suggestions, and/or questions regarding the meeting?

10. In which country are you based?

11. What is your main occupation/affiliation?
   - Hospital / clinic
   - Community-based organization / PLHIV
   - Academia: university, research institute, etc.
   - Industry – ARVs
   - Governmental
   - Industry – Other
   - Non-governmental

12. Which events do you generally attend?
   - International AIDS Conference
   - CROI
   - IAS Conference on HIV Pathogenesis, Treatment and Prevention
   - ICAP
   - International Workshop on HIV Pediatrics (Virology Education)
   - ICASA
   - Virology education events (other than the Intl. Workshop on HIV Pediatrics)
This meeting was organized by the International AIDS Society-Industry Liaison Forum (IAS-ILF) and the IAS’s Collaborative Initiative for Paediatric HIV Education and Research (CIPHER).

The IAS-ILF is a mechanism to inform and support collaboration and partnership between industry and the IAS. Guided by a strong, multi-stakeholder advisory group, it performs this broad task by regularly providing opportunities for industry to understand the IAS’s interests and priorities, and vice versa, seeking common ground to enhance the impact of our response to HIV and related co-morbidities.

CIPHER is aimed at optimizing clinical management and delivery of services to infants, children and adolescents affected by HIV in resource-limited settings through advocacy and research promotion.

International AIDS Society
Avenue de France 23
CH-1202 Geneva
Switzerland

Tel: +41 22 710 08 00
Fax: +41 22 710 08 99

ias@iasociety.org
www.iasociety.org