

Meeting Brief

Stakeholders Meeting on Increasing Financing for Type 1 Diabetes Mellitus Children in India (2nd Meeting)

Date: 28th August 2023, Friday | **Time:** 08:00 – 09:00 pm | **Location:** Virtual Zoom meeting

People to People Health Foundation (PPHF) convened 2nd meeting of stakeholders on “**Working together to increase financing for Type 1 Diabetes Mellitus children in India**” on **Friday, August 28, 2023**. The purpose of the meeting was to discuss the foundational aspects of the Action Groups. It was focused on key agenda items to establish a strong framework and direction for the group's activities.

Meeting Agenda items

1. Review and finalize the Terms of Reference (ToR) of the Action Groups.
2. Membership for Action Groups.
3. Discuss high-priority activities (short term and medium term) with tentative workplan with timeline.

Summary of Discussion:

The meeting commenced with a review of the agenda items from the previous session. PPHF team briefly stated the overall purpose of the meeting. The key highlights from the discussion are as follows:

1) Finalization of Terms of Reference (ToR) for the Task Force Group

The group revisited the purpose of the task force which primarily work towards raising awareness, foster collaboration, and advocate for improved programs on T1D. The focus of the platform is bringing together key stakeholders to advocate for improved policies, programs and increased financing on T1D. Besides that the platform will engagement key stakeholders for the execution of a nationwide assessment on T1D prevalence, development and dissemination of position papers and policy recommendations based on the contemporary evidence.

2) Operating Model and High-priority activities of the Task Force Group

During the meeting, the operational framework and the functions of the Action Groups and Secretariat were discussed. Smaller action groups, each comprised of 5-6 subject matter experts and members will be established to focus on distinct sub-themes. These **sub-themes** include financing, livelihood models, access to medicine, supply chain, and insurance. The high-priority activities that have been established in the first meeting were reviewed. The

Secretariat will be responsible for providing administrative and content support to Action Groups and facilitating services to members. The Secretariat will be responsible for regular day-to-day decision making in running the activities. Refer **Annexure 1** for high priority activities of the action groups)

3) Circulation of google form and gathering responses.

To gather additional insights, a Google form was circulated to all participants including those who could not attend the meeting. Participants expressed their interest in joining a specific group or nominate individuals for group membership. Refer **Annexure 1** for summary of google survey.

4) Summary of additional Suggestions Discussed

- a) The importance of prevalence studies in assessing the overall burden of Type 1 Diabetes, aiding healthcare professionals, policymakers, and researchers to improve the quality of care and support.
- b) Collaboration, networking and leveraging diabetes education and awareness are integral components of a holistic approach to Type 1 Diabetes care.
- c) Public Private Partnership (PPP) bridges the private and government sectors pooling resources for improved outcomes.
- d) Additionally, livelihood programs and regional support initiatives contribute to the overall well-being of Type 1 diabetes patients and their families, extending care beyond medical treatment. The best practices of few partners could be visited to capture learnings and sharing with the larger stakeholders.

Annexure I

Summary from Task Force Group Survey Responses in Google form Activities for Acton Groups (Short-term, Medium-term, Long-term)

The table below summarizes activities drafted by PPHF and the responses received from the participants.

Sl. No.	Short-term Activities	Medium-term Activities	Long-term Activities
	Activities discussed during meeting		
	1-12 months	12-36 Months	3 to 5 years
1	Establish a secretariat.	Bring Type 1 DM into the public and political domain.	Opportunities for establishing and improving legislations, policies and implementation practices.
2	Develop strategy for Task Force Group (operating model, membership).	Higher budgetary allocation for Type 1 DM interventions.	Regularly conduct events, seminars and conferences serving as a platform for networking and knowledge exchange amongst members.
3	Formation of action groups on themes or subthemes (e.g., financing, livelihood models, access to medicine, supply chain etc.)	Increasing access to affordable and quality medication for Type 1 DM.	Provide opportunities for members to voice their concerns.
4	Support action groups meetings and assist in implementation of activities.	Increase community awareness and access to related services.	Facilitate design and maintenance of a KM portal and ensure effective capturing and sharing of knowledge with members.
5	Develop knowledge products, publications, position papers. technical briefs and other resource material.	Improve supply chain for sustainable access to Type 1 DM medicines and availability of diagnostics.	
6	Organize an annual conference on critical topics of importance to the national program and policy stakeholders.	Improve Health Management Information System to have better epidemiological data on Type 1 DM for better programming	
7	Active participation in govt. forums, meetings and other engagements to ensure the achievement of desired objectives.	The group will have a mandate for influencing all relevant stakeholders in driving successful T1D outcomes.	
8	Develop knowledge products, publications, position papers. technical briefs and other resource material.		
Additional activities proposed by Participants			
1	Publish Position Statement	Conduct Pan India studies and research on prevalence of T1D.	Influence policymakers for T1D care and advocacy (Ex: GST reduction, access, additional financing provisions)
2	Advocacy for insulin and glucostrips access	Promote ISPAD LMIC T1D guidelines	Advocate for insulin pump and CGMS for all
3	Education campaigns and support	Promote annual drive for HbA1c test.	Comprehensive T1D training, helpline, awareness

4	Raise awareness in schools	Advocate for Inclusion of Insulin and CGM in Essential Medicines List	School support, teacher education
5	Prepare a funding resource for Type 1	Promote integration of technology for remote care	Develop public awareness
6	Conduct CMEs for healthcare professionals	Develop SOPs and guidelines for SHG.	Implement T1D registry, EMR,
7		Engage with Parliamentarians to increase attention on T1D	National CME, consensus, recommendations, resources
8		Sensitize government, secure funding	
9		Advocate for Collecting nationwide T1D data for assessing prevalence.	
10		Increase access to resources for underprivileged	

Nomination for Action Groups

Sl. No.	Action Group Name	No. of person suggested
1	Financing	9
2	Insurance	5
3	Livelihood Models	8
4	Awareness & education	17
5	Access to medicine	11
6	Supply Chain	6
7	Comprehensive Adolescent Health	1
8	Type 1D Parents	1
9	Mental Health	0

Name of the Platform

Participants suggested various names for the platform; however, we brainstormed and shortlisted 2 names suitable for the Platform:

- 1. LEAD Alliance-** Leadership and Empower Action for Diabetes (Type 1)- most preferred
- 2. DEESHA-** Diabetes (Type1) Education and Empowerment Strategic Health Alliance

Nominations of New Stakeholders

Participants nominated several stakeholders and names of institutes from which people were nominated are listed below.

1. IJCP Group, New Delhi.
2. AIIMS, New Delhi & Bathinda.
3. Government representatives from Central and state (working on Type 1)
4. Media

5. NGO
6. International development partners
7. UN agencies
8. Dept of Women and child health care (Central Govt)
9. Health & Family welfare (State Government)

The responses from the participant provided were valuable insights into the priorities, activities, and nominations for the Type 1 Diabetes Task Force Group. The suggestions and recommendations will be instrumental in shaping the mission of the group in its efforts to improve the lives of children with Type 1 Diabetes Mellitus in India.

Next Steps

- Formation and Announcement of Action groups and its members.
- Identification of high-priority activities for action groups.

Annexure 2

List of Participants*(Names are arranged in alphabetic orders)

1. Dr A. Mythili, Diabetic Child Society
2. Dr Alok Kanungo, Dr Kanungo'S Diabetes Centre
3. Mr. Amit Sharma, DexCom
4. Dr Anil Kumar Vedwal, Yog Dhyan Foundation
5. Dr Anish Ahamed, Endodiab Perinthalmanna Charitable Society
6. Dr Anju Vermani, Yog Dhyan Foundation
7. Dr Archana Sarda, Udaan
8. Ms. Asawari Sathaye, OPPI
9. Dr Avula Laxmaiah, Ex.National Institute of Nutrition (NIN)
10. Dr Banshi Saboo, Diacare
11. Dr Baridalyne Nongkynrih, AIIMS, New Delhi.
12. Mr. Dinu Rema Surendran, Medtronic
13. Mr. Diwakar Mittal, Novo Nordisk
14. Mr. Indrajit Majumdar, Diabetes Awareness & You
15. Dr Jayshree Swain, Association for Voluntary Action
16. Dr Jothydev Kesavadev, Jothydev'S Diabetes and Research Centre
17. Dr Kavita Chaudhry, Sanofi
18. Dr Krishnan Swaminathan, Idhayangal Charitable Trust
19. Mr. Lakshminarayana Varimadugu
20. Ms. Mridula Bhargava, Diabetes Fighters Trust
21. Ms. N. Subhashini Devi, Nityaasha

22. Ms. Nargis Akhtari, Dr Kanungo'S Diabetes Centre
23. Ms. Nupur Lalvani, Blue Circle Foundation
24. Dr P.V Rao, Diabetes Research Society
25. Mr. Prabhat Sinha, Boehringer Ingelheim India
26. Mr. Prashant Mani, Tamil Nadu T1 Foundation
27. Mr. Prashant Sharma, Medtronic
28. Mr. Prasun Sarkar, ICICI Prudential Life Insurance Company limited
29. Dr Radha Valauikar, Piramal Foundation
30. Dr Rakesh Kumar, Association for Children with Type 1 Diabetes
31. Dr Rakesh Sahay, Osmania Medical College & Osmania General Hospital, Hyderabad
32. Mr. Ramesh Ch Jana, Endeavour Foundation & Trust
33. Dr Sabine Kapasi, UN - WHO - MoHFW - Wharton School - HBS - NUS - Ashoka.
34. Dr Sanjay Kalra, Bharti Hospital, Karnal
35. Dr Santhosh OS, Karnataka Institute of Endocrinology & Research, Bangaluru
36. Mr. Sarvjeet
37. Dr Sirisha Kusuma Boddu, Rainbow Children's Hospital
38. Ms. Snehal Nandagawli, Blue Circle Diabetes Foundation
39. Dr Suchy Chugh, Novo Nordisk
40. Dr V. Mohan, Diabetes International Research Educational and Charitable Trust
41. Mr. Vikrant Shrotriya, Novo Nordisk India

PPHF Team

42. Mr. Ajay Pal
43. Ms. Arushi Kaur,
44. Mr. Chandra Nath Mishra
45. Ms. Ifra Yusuf
46. Ms. Kritika Banerjee
47. Dr. Laxmikant Palo
48. Mr. Mohammad Aleem
49. Dr. Mounika Pydipalli
50. Mr. Nitin Bhardwaj
51. Dr. Sona Deshmukh
52. Mr. Usman Siddiqui