

ORDI – Advocacy Committee

1. BRIEF INTRODUCTION

The purpose of constituting a PAG Advocacy Committee is to create joint responsibility and unite disease specific disease patients or specific Patient Advocacy groups operating regionally or nationally, under one umbrella, united towards the common cause of fighting for the rights of patients of all rare diseases. The aim is to #CareforRare and #LeaveNoDiseaseBehind and ensure that national decisions are made in a consultative and inclusive manner.

2. RULES FOR ORDI- ADVOCACY COMMITTEE

a. ELIGIBILITY –

- i. This is by invitation from ORDI
- ii. Patient Advocacy Groups ('PAGs') that have filled in the ORDI membership form and completed the formalities thereof are eligible to nominate a person from their group on receipt of invitation from ORDI
- iii. Patients (in absence of formal PAG/ support group) are eligible for invitation.
- iv. All persons above age 18 years are eligible

b. COMPOSITION –

- i. The ORDI-ADVOCACY COMMITTEE shall be composed of 5-7 members initially, out of which 1 member must be an adult patient from either ORDI or its member PAGs.
- ii. There shall be one member from ORDI on the ORDI-ADVOCACY COMMITTEE.

c. TERM OF OFFICE –

- i. Members of the ORDI- ADVOCACY COMMITTEE will hold office for a period of 1 year.

d. INTERNAL STRUCTURE –

- i. The ORDI-ADVOCACY COMMITTEE shall have a Chairperson

e. The committee shall meet at least once a month or as required. (Physically / Virtually)COPE OF WORK –

- i. ORDI-ADVOCACY COMMITTEE shall work on the needs and current challenges faced by the Rare Diseases and PAG community.

- ii. ORDI-ADVOCACY COMMITTEE work exclusively on all Govt. Policy advocacy works (Central and State). They shall meet Govt Officials on behalf of this Committee.
- iii. ORDI- ADVOCACY COMMITTEE shall decide on the communication (Letters, Suggestion, E Mail, Content etc) to govt jointly and only this will be presented on behalf of all Rare Disease Community. The Committee shall send draft of such communication to all its members.
- iv. All such communications are jointly signed by Committee Chairman and Executive Director /CEO of ORDI.
- v. Directors, Members, Staff, Other Advisors of ORDI shall be eligible to participate in the ORDI- Advocacy Committee meetings.
- vi. Advice ORDI on Joint action plan for achieving and accomplishing the needs of PAG Community
- vii. Attend meetings and discussions at forum of common interest of the PAG
- viii. Update all PAG on the current status of National Policies of the Govt and those being perused collectively.

f. RELATIONSHIP WITH ORDI

- i. ORDI-ADVOCACY COMMITTEE shall operate under the national umbrella of ORDI.
- ii. There shall be consultation with ORDI on the documents, initiatives and working of ORDI-ADVOCACY COMMITTEE.
- iii. The activities of ORDI-ADVOCACY COMMITTEE shall not interfere with ORDI's vision and mission and any of the existing and resulting activities, Regular plans programmes and initiatives. Similarly ORDI will not interfere in working of respective committee member's organization.
- iv. ORDI-ADVOCACY COMMITTEE shall work on the needs and current challenges faced by the PAG community.

g. RE-NOMINATION PROCEDURES –

- i. ORDI can re invite a member of ORDI-ADVOCACY COMMITTEE not more than 2 years. They shall eligible to re invite after min of 1-year gap.

h. REMOVAL FROM ORDI-ADVOCACY COMMITTEE (GROUNDS, METHOD) –

- i. A member of ORDI-ADVOCACY COMMITTEE may be removed by a simple majority vote of the ORDI Advocacy Committee members or ORDI Directors.
- ii. Grounds for removal include:
 - 1. Evidence of illegal or unlawful activity is presented
 - 2. Evidence of unlawful enrichment or syphoning of funds

3. Conflict of Interest due to relationship with Pharmaceutical company/medical fraternity
4. Non-participation or disruption of meetings/initiatives more than 3 times
5. Breach of Patient rights, data protection laws on patient data and patient privacy
6. Other grounds as reasonable in the laws of India.
7. Any other activity against the Vision, Mission and Objective of ORDI

iii. The ORDI-Advocacy Committee May also be dissolved by ORDI-Board.

i. MEETINGS AND REPORTING -

- i. ORDI- ADVOCACY COMMITTEE shall meet physically / virtually once a month. Or whenever there is a urgency on a short notice
- ii. Internal procedure and voting may be decided by ORDI- ADVOCACY COMMITTEE.
- iii. ORDI- ADVOCACY COMMITTEE shall submit monthly reports of its functioning and activities to all PAG members.

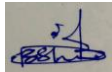
j. LEGALITIES (INTELLECTUAL PROPERTY, CONTRACTS WITH THIRD PARTIES, CONFLICT OF INTEREST):

- i. ORDI shall retain ownership of all intellectual property emanating out of the ORDI- ADVOCACY COMMITTEE and its meeting. This includes but is not limited to initiatives, programmes, activities and policy documents/letters.
- ii. ORDI- ADVOCACY COMMITTEE shall not enter into any contracts on behalf of ORDI or the rare disease community in India or abroad without ORDI approval in writing. ORDI is not bound to enter any such contracts and may choose to decline entering into any legal arrangement. ORDI- ADVOCACY COMMITTEE may advise ORDI regarding such legal arrangements.
- iii. No individual member shall claim or use, the discussions and outcome without information to the committee.
- iv. **Conflict of Interest Disclosures** – All members who accepts the invitation shall declare conflicts of Interest (if any) and their various institutional affiliation in any level. Where any member of the ORDI-ADVOCACY COMMITTEE has an arrangement or relationship with a pharmaceutical company that personally enriches them, they must disclose the same. The said member is not part of any other group in India/ Abroad.

- v. **Data Protection** – Data Protection for all patient data, which may include sensitive personal data, personal data, photographs, case document etc must be protected. ORDI shall not bear the responsibility of any injury or harm caused due to their use, transmission or sharing.
- vi. **All members are bound to the confidentiality of all information of the discussion, disclose to them, known to them during transaction.** Only official information shall be communicated to other ORDI members and PAG's. Committee Chairman or Executive director/CEO is authorised person to communicate.

For ORDI

Date: 2nd Nov 2020



Prasanna Shirol
Co founder and Executive Director

Acknowledgement and Acceptance

I the undersigned Mr /Mrs _____

From _____ Diseases/Support group / PAG hereby accepts the invitation and terms and conditions.

I further confirm that, I have approval of my organization/group members.

For _____

Mr/Mrs _____
(Seal of the organization)