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EURORDIS RARE DISEASES EUROPE SGA 2018

JA2015 - GPSD [705038]

START DATE: 01/01/2018

END DATE: 31/12/2018

DURATION: 12 month(s)

CURRENT STATUS: Finalised

PROGRAMME TITLE: 3rd Health Programme (2014-2020)

PROGRAMME PRIORITY: -

CALL: Financial contribution to the functioning of non-governmental bodies
(Operating grants)

TOPIC: Specific Grant Agreements under HP-FPA-2017

EC CONTRIBUTION: 1027785 EUR

KEYWORDS: Operating Grant, Rare Diseases, Specific Grant Agreement

Project abstract

The EURORDIS Specific Grant Agreement 2018 is the first SGA within the overarching Framework Partnership Agreement 2018-2021. EURORDIS main strategic objectives are to consolidate the Rare Disease patient's community and strengthen the rare disease patients' voice; to actively engage rare disease patient representatives into the effective implementation and monitoring of relevant legislation/strategies; to build capacities and empower rare disease patients advocates, members and volunteers; to sustain human, financial and organisational resources. All activities within the SGA 2018 work to this effect.

Work package

Work Package 1: Consolidate the rare disease patients' community

Start month: 1

End month: 12

Work Package Leader: EURORDIS

Consolidate the rare disease patients' community through:

- EURORDIS membership and outreach to rare disease patient organisations (POs).
- Outreach & support to rare disease patient groups at international level
- Raising public awareness through Rare Disease Day (RDD) 2018 and planning of RDD 2019
- Producing, disseminating and exchanging information and experiences
- Providing a platform for multi-stakeholder dialogue on rare diseases through the European Conference on Rare Diseases and Orphan Products (ECRD) 2018

Work Package 2: Actively engage RD patient representatives into the effective implementation and monitoring of legislation and strategies

Start month: 1

End month: 12

Work Package Leader: EURORDIS

Actively engage RD patient representatives into the effective implementation and monitoring of legislation and strategies through:

- Supporting the development of EU/national health care policies addressing the needs of PLWRD
- Supporting patient involvement in EMA activities
- Supporting patient involvement in European HTA Network, EUnetHTA JA3 and related HTA activities
- Supporting patient involvement in quality information on medicines through the EURORDIS Drug Information Transparency & Access Task Force (DITA TF) and the review of public information on medicines (EPARs, package leaflets, PSOs)
- Supporting patient engagement in promoting access to rare disease therapies

Work Package 3: Build capacities and empower members and volunteers

Start month: 1

End month: 12

Work Package Leader: EURORDIS

Build capacities and empower members and volunteers through:

- Capacity-building of members, new and small patient organisations:
- Capacity-building of European Networks: Council of National Alliances (CNA), Council of European Federations (CEF) and European Network of Rare Disease Help Lines (ENRDHL): networking, exchange, training
- Capacity-building of patient advocates through the EURORDIS Open Academy
- Conducting at least 3 surveys on patient perspectives regarding their experience, needs & expectations

Work Package 4: Sustain human, financial and organisational resources

Start month: 1

End month: 12

Work Package Leader: EURORDIS

Sustain human, financial and organisational resources through:

- Identifying, involving and supporting volunteers
- Ensuring good financial management and transparency
- Enhancing quality governance

Work Package 5: Management of SGA 2018

Start month: 1

End month: 12

Work Package Leader: EURORDIS

Management of the Specific Grant Agreement. One on one meetings will take place with responsible managers, in addition to the Financial Director. Regular group meetings of the SGA 2018 Steering Committee Meeting will also take place (4 meetings, with 6 most responsible managers in SGA implementation). Reporting will take place and be uploaded to CHAFEA's electronic platform throughout the year.

Work Package 6: Evaluation of SGA 2018

Start month: 10

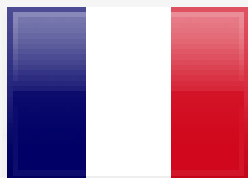
End month: 12

Work Package Leader: EURORDIS

. Perform the evaluation of EURORDIS activities against the annual work plan 2018. EURORDIS will produce a public layman's summary of the final evaluation report.

The Layman's summary will be based on the final Reports of the Specific Grant 2018 which comprise: Technical Report, Financial Report, and Contractual Annexes. These include a comprehensive list of output, process, impact indicators. The Report will be disseminated to CHAFEA two months after the completion of the SGA

COORDINATOR



EURORDIS - EUROPEAN ORGANISATION FOR RARE DISEASES
ASSOCIATION (EURORDIS)

96 rue Didot
75014 Paris

France

WEBSITE: <http://www.eurordis.org>

PARTNERS

No partners related to the current project

Evaluation Report of SGA 2018: Layman's Summary

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 08/03/2019

EURORDIS will produce a public layman's summary of the final evaluation report. The layman's summary will be based on the final Reports of the Specific Grant 2018 which comprise: Technical Report, Financial Report, and Contractual Annexes.

EURORDIS Open Academy

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 08/03/2019

All material presenting the concept and planning of the EURORDIS Open Academy will be provided, including an outline of all training face-to-face or online organised in its framework. In addition, any publicly available printed and online material produced within the EURORDIS Academy will also be provided. For the EURORDIS ExPRESS Summer School these entail: a) EURORDIS Summer School Programme b) EURORDIS Summer School Flyer c) EURORDIS Summer School Presentations d) Screenshot of online training section

EURORDIS good governance procedures

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 08/03/2019

a) Governance Chart 2018 b) Representation Chart 2018 c) Team Chart 2018 d) Action Plan 2018 & Budget e) EURORDIS By-laws

EURORDIS online & printed communication materials & tools

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 07/03/2019

a) 11 monthly eNews reports in 7 languages b) 22 bi-monthly Member news

reports in 6 languages c) EURORDIS website in 7 languages d) EURORDIS Activity Report 2017 e) EURORDIS social media f) List of webinars, topics addressed and target audience

ECRD Vienna 2018

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 07/03/2019

a) List of ECRD 2018 Vienna Official and Associated Partners b) List of members of Programme Committee ECRD 2018 Vienna c) Website for ECRD 2018 Vienna and other communication tools (mobile app) d) Programme of ECRD 2018 Vienna e) Conference report

Patient Engagement in ERN & Healthcare Pathways

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 07/03/2019

a) List of 24 ePAGs b) List of ePAG representatives per ePAG c) List of Working Groups transversal to ePAGs d) List of ePAG webinars e) ePAG representatives meetings agenda and list of participants f) List of capacity-building meetings for NAs g) ePAGs Terms of Reference

Patient engagement in advice & assessment of product lifecycle (EMA, HTA)

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 07/03/2019

A report will be produced on EURORDIS support to Patient engagement in advice & assessment of product lifecycle (EMA, HTA) for the SGA

EURORDIS monthly Therapeutic reports

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 07/03/2019

11 Monthly therapeutic reports: EURORDIS produces therapeutic reports on a monthly basis (except August). These reports are disseminated to patient representatives participating at the EMA, the EURORDIS TAG, the EURORDIS

BoD, the European Public Affairs Committee (EPAC), the EURORDIS Summer School Alumni (a total of 350 individuals), in addition to the EURORDIS membership at large via the Member News. In 2018 there will be 11 therapeutic reports: 3 examples will be provided

Meetings of European Networks (CNA, CEF, ENRDHL)

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 07/03/2019

CNA: 2 meetings of the Council of National Alliances will be held in 2018 a) CNA meeting in March 2018, a report will be produced by July (with validation time for NAs) b) CNA meeting in Paris in October 2018, a report will be produced by December CEF: 1 meeting of the Council of European Federations will be held in 2018, back to back with the CNA meeting in Paris in October 2018. Following the meeting a report will be produced. c) CEF meeting agenda d) Report of CEF meeting e) List of members of CEF f) List of meetings organised under the programme "Support to European Rare Disease Federations" ENRDHL: 1 meeting of the ENRDHL will be held in 2018 g) Caller Profile Analysis results

EURORDIS Membership

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 06/03/2019

a) EURORDIS membership list b) EURORDIS membership growth c) EURORDIS contact database

Rare Disease Day 2018 materials

EURORDIS

EURORDIS RARE DISEASES EUROPE SGA 2018 (EURORDIS SGA FY2018)

Published on: 06/03/2019

a) RDD 2018 Poster and visual identity b) RDD 2018 Info pack c) RDD 2018 Website: the dedicated RDD website is sustained throughout the year and updated yearly around RDD d) RDD 2018 social media: such as the RDD dedicated Facebook page and Twitter feed e) RDD 2018 Video: the video will be made publicly available 2 weeks before Rare Disease Day 2018 and will be translated in more than 30 languages.