



RARE
DISEASES
INTERNATIONAL

Financial Report 2022

RARE DISEASES INTERNATIONAL

Association governed by the French law of July 1, 1901

96, Rue Didot

75014 PARIS

Statutory auditor's report on the financial statements

For the year ended December 31, 2022

This is a translation into English of the statutory auditors' report on the financial statements of the association issued in French and it is provided solely for the convenience of English-speaking users.

This statutory auditors' report includes information required by French law, such as information about the appointment of the statutory auditors or verification of the management report and other documents provided to stakeholders.

This report should be read in conjunction with, and construed in accordance with, French law and professional auditing standards applicable in France.

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Statutory auditor's report on the financial statements

For the year ended December 31, 2022

To the annual general meeting of Rare Diseases International,

Opinion

In compliance with the engagement entrusted to us by your annual general meeting, we have audited the accompanying financial statements of Rare Diseases International for the year ended December 31, 2022.

In our opinion, the financial statements give a true and fair view of the assets and liabilities and of the financial position of the Association as of December 31, 2022 and of the results of its operations for the year then ended in accordance with French accounting principles.



Basis for Opinion

Audit Framework

We conducted our audit in accordance with professional standards applicable in France. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Our responsibilities under those standards are further described in the “*Statutory Auditor’s Responsibilities for the Audit of the Financial Statements*” section of our report.

Independence

We conducted our audit engagement in compliance with independence requirements of the French Commercial Code (code de commerce) and the French Code of Ethics (code de déontologie) for statutory auditors, for the period from January 1, 2022 to the date of our report.

Justification of Assessments

In accordance with the requirements of Articles L. 823-9 and R. 823-7 of the French Commercial Code (code de commerce) relating to the justification of our assessments, we inform you that the assessments made by us focused on the appropriateness of the accounting principles used, the reasonableness of accounting estimates and the overall financial statements’ presentation.

These matters were addressed in the context of our audit of the financial statements as a whole, and in forming our opinion thereon, and we do not provide a separate opinion on specific items of the financial statements.

Specific verifications

We have also performed, in accordance with professional standards applicable in France, the specific verifications required by French law.

We have no matters to report as to the fair presentation and the consistency with the financial statements of the information given in the management report of the Board of Directors and in the other documents with respect to the financial position and the financial statements provided to the members.

Responsibilities of Management and Those Charged with Governance for the Financial Statements

Management is responsible for the preparation and fair presentation of the financial statements in accordance with French accounting principles, and for such internal control as management determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, management is responsible for assessing the Association’s ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless it is expected to liquidate the Association or to cease operations.

The financial statements were approved by the board of directors.



Statutory Auditor's Responsibilities for the Audit of the Financial Statements

Our role is to issue a report on the financial statements. Our objective is to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with professional standards will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

As specified in Article L. 823-10-1 of the French Commercial Code (*code de commerce*), our statutory audit does not include assurance on the viability of the Association or the quality of management of the affairs of the Association.

As part of an audit conducted in accordance with professional standards applicable in France, the statutory auditor exercises professional judgment throughout the audit and furthermore:

- Identifies and assesses the risks of material misstatement of the financial statements, whether due to fraud or error, designs and performs audit procedures responsive to those risks, and obtains audit evidence considered to be sufficient and appropriate to provide a basis for his opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control;
- Obtains an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the internal control;
- Evaluates the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by management in the financial statements;
- Assesses the appropriateness of management's use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the Association's ability to continue as a going concern. This assessment is based on the audit evidence obtained up to the date of his audit report. However, future events or conditions may cause the Association to cease to continue as a going concern. If the statutory auditor concludes that a material uncertainty exists, there is a requirement to draw attention in the audit report to the related disclosures in the financial statements or, if such disclosures are not provided or inadequate, to modify the opinion expressed therein;
- Evaluates the overall presentation of the financial statements and assesses whether these statements represent the underlying transactions and events in a manner that achieves fair presentation.

Paris-La Défense, May 22, 2023

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY



| Assets | 2021 | 2022 | Δ in euros | Δ in % |
|--|----------------|----------------|-----------------|-------------|
| FIXED ASSETS | | | | |
| Intangible assets | 0 | 0 | 0 | NA |
| Tangible assets | 0 | 0 | 0 | NA |
| Financial assets | 0 | 0 | 0 | NA |
| TOTAL | 0 | 0 | 0 | NA |
| CURRENT ASSETS | | | | |
| Account receivable due within one year | 459 171 | 40 000 | -419 171 | -91% |
| Account receivable due after one year | 0 | 0 | 0 | NA |
| Other receivables | 9 440 | 6 472 | -2 968 | |
| Liquid assets | 431 529 | 469 597 | 38 068 | 9% |
| Prepaid expenses | 449 | 224 | -226 | -50% |
| TOTAL | 900 589 | 516 292 | -384 296 | -43% |
| Conversion adjustment | 0 | 0 | 0 | NA |
| TOTAL ASSETS | 900 589 | 516 292 | -384 296 | -43% |

| Liabilities | 2021 | 2022 | Δ in euros | Δ in % |
|------------------------------------|----------------|----------------|-----------------|-------------|
| ASSOCIATION FUNDS | | | | |
| Reserve | 162 862 | 297 836 | 134 974 | 83% |
| Profit & loss for the year | 134 974 | 42 955 | -92 019 | -68% |
| Subsidies of investment | 0 | 0 | 0 | NA |
| TOTAL | 297 836 | 340 791 | 42 955 | 14% |
| Provisions for risk and charges | 1 928 | 2 951 | 1 023 | 53% |
| Dedicated funds on grants | 0 | 0 | 0 | NA |
| DEBTS | | | | |
| Bank loans and overdraft | 0 | 0 | 0 | NA |
| Trade creditors | 125 412 | 33 445 | -91 966 | -73% |
| Tax payable and social liabilities | 21 460 | 33 597 | 12 137 | 57% |
| Other debts | 6 583 | 11 400 | 4 817 | 73% |
| Deferred income within one year | 447 370 | 94 108 | -353 262 | -79% |
| Deferred income after one year | 0 | 0 | 0 | NA |
| TOTAL | 602 752 | 175 502 | -427 251 | -71% |
| Conversion adjustment | 0 | 0 | 0 | NA |
| TOTAL LIABILITIES | 900 589 | 516 292 | -384 296 | -43% |



**2022 Financial Status
VS 2021 Financial Status**
(Profit and Loss including in kind contributions)

| Revenue | 2021 Fin. Status | 2022 Fin. Status | Ratio | Δ in euros | Δ in % |
|------------------------------------|---------------------|---------------------|-------------|----------------|------------|
| Patient Organisations | 205 262 | 241 097 | 16% | 35 835 | 17% |
| In kind contributions (EURORDIS) | 198 600 | 233 236 | 15% | 34 635 | 17% |
| Membership fees | 6 662 | 7 862 | 1% | 1 200 | 18% |
| Volunteers | 307 311 | 315 903 | 21% | 8 592 | 3% |
| Volunteers | 307 251 | 315 753 | 21% | 8 502 | 3% |
| Donations | 60 | 150 | 0% | 90 | 150% |
| Health Corporations | 509 668 | 616 648 | 40% | 106 980 | 21% |
| Pharma. and Biotech Companies | 509 668 | 616 648 | 40% | 106 980 | 21% |
| Other Health Sector Corporates | | | | | |
| Outside Health Corporates and NPOs | 101 200 | 353 771 | 23% | 252 571 | 250% |
| Outside Health Sector Corporates | 1 200 | 55 965 | 4% | 54 765 | 4564% |
| Pharma. and Biotech Found. | | 20 000 | 1% | 20 000 | |
| Other Health Sector NPOs | | 1 050 | 0% | 1 050 | |
| Outside Health Sector NPOs | 100 000 | 276 757 | 18% | 176 757 | 177% |
| Miscellaneous | 311 | 3 071 | 0% | 2 759 | 886% |
| Reimbursement | | | | | |
| Others | 311 | 3 071 | 0% | 2 759 | 886% |
| Exceptional income | | | | | |
| Honoraries | | | | | |
| Others fees | 311 | 15 | 0% | -296 | -95% |
| Financial assets | | 3 056 | 0% | 3 056 | |
| Sub-total | 1 123 752 | 1 530 490 | 100% | 406 737 | 36% |
| Recovery of provisions | | | | | |
| Report of non-used income | | | | | |
| Total Revenue | 1 123 752 | 1 530 490 | | 406 737 | 36% |

| Expenses | 2021 Fin. Status | 2022 Fin. Status | Ratio | Δ in euros | Δ in % |
|--|---------------------|---------------------|-------------|----------------|-------------|
| Staff | 405 220 | 672 771 | 45% | 267 551 | 66% |
| Wages and charges | 282 256 | 406 835 | 27% | 124 579 | 44% |
| Other salaries | 120 712 | 261 992 | 18% | 141 280 | 117% |
| Training and other costs | 2 252 | 3 945 | 0% | 1 692 | 75% |
| Volunteers | 307 251 | 315 753 | 21% | 8 502 | 3% |
| Representatives and task forces | 297 863 | 311 903 | 21% | 14 039 | 5% |
| Projects, office and translators | 9 388 | 3 850 | 0% | -5 538 | -59% |
| Logistics | 47 338 | 263 353 | 18% | 216 015 | 456% |
| Travels and subsistence | 37 338 | 118 984 | 8% | 81 645 | 219% |
| Event logistics and catering | 10 000 | 28 315 | 2% | 18 315 | 183% |
| Virtual events | | 116 054 | 8% | 116 054 | |
| Services | 220 900 | 226 409 | 15% | 5 510 | 2% |
| Fees | 218 520 | 205 552 | 14% | -12 968 | -6% |
| Partners | | 16 000 | 1% | 16 000 | |
| Telecom and post | 1 562 | 2 688 | 0% | 1 126 | 72% |
| Rent | | | | | |
| Other services | 817 | 2 169 | 0% | 1 352 | 165% |
| Purchase | 4 924 | 4 663 | 0% | -260 | -5% |
| Office furniture | 1 203 | 1 940 | 0% | 737 | 61% |
| Communications, Publications | 2 760 | 1 882 | 0% | -879 | -32% |
| Other purchases | 960 | 842 | 0% | -118 | -12% |
| Miscellaneous | 1 218 | 3 562 | 0% | 2 343 | 192% |
| Financial expenses, Insurance, Tax | 1 218 | 3 562 | 0% | 2 343 | 192% |
| Exceptional expenses | | | | | |
| Sub-total | 986 850 | 1 486 511 | 100% | 499 661 | 51% |
| Contingency and loss provisions | 1 928 | 1 023 | 0% | -905 | -47% |
| Commitment on assigned income | | | | | |
| Total Expenses | 988 778 | 1 487 535 | | 498 756 | 50% |
| Result | 134 974 | 42 955 | | | |

1. Assets and Liabilities

The assets and liabilities of RDI amounted to 516 k€ at the end of 2022 compared to 901 k€ at the end of 2021.

As RDI has no fixed assets (such as computers, office furniture which are being provided by EURORDIS) and no pluriannual contracts signed with a donor, the bulk of this amount consists of liquidities (470 k€) and accounts receivable within one year (40 k€) in terms of assets, and mainly association funds (341 k€) and deferred income (94 k€) in terms of liabilities.

2. Income

In 2022, RDI's income came from three sources:

- Patient Organisations and Volunteers (37%)
- Donations from Foundations and Outside Health Sector Corporations (23%)
- Donations from Pharmaceutical Companies (40%)

2.1. Patient Organisations

Consists of membership fees (8 k€ in 2022 vs 7 K€ in 2021) and in-kind contribution from EURORDIS (233 k€ in 2022 vs 198 k€ in 2021, a 17% increase).

In 2022, out of 81 members, 47 paid their membership fees.

EURORDIS provided the following in-kind contribution to support RDI:

- Staff (132 k€) consisting of salaries and social charges of an Executive Director, Flaminia Macchia, full time (1 FTE)
- the infrastructure (102 k€) is a reasonable estimate of actual costs: office space; IT equipment and assistance; payroll and staff management of staff on EURORDIS' payroll as well as on RDI's payroll; budget monitoring; accounting and cash management; hosting and technical support of RDI's website. The amount of this in-kind contribution has been calculated by evaluating the cost for EURORDIS for all those activities, dividing it by 56¹ and multiplying it by 8 FTE at RDI. Our calculations showed a yearly cost of roughly 12 k€ per FTE + roughly 6 k€ for the website.

2.2. Volunteers

The economic value of volunteer's time is worth 316 K€ in 2022, an increase of +3% vs 2021.

All volunteers reported their time spent in 2022, validated by the Secretariat.

79 patient representatives, 1 Office volunteer and 7 Council volunteers for 4875 hours and corresponding to 3 FTE.

The number of hours has been multiplied by an hourly rate.

Patient representatives and experts all have the same hourly rate which is an average of the hourly rate of patient representatives in similar organisations (65 €).

2.3. Pharmaceutical companies

In 2022, the donations received from that sector amounted to 617 k€ (vs 510 k€ in 2021 a +21% increase) broken down as followed:

- 320 k€, Alliance of Companies, by 16 companies 20 K€ each, unrestricted
- 116k€ of In-Kind from Alexion in the context of the Rare Disease Day event in Dubai
- 95 k€, Capacity Building Programmes

¹ The Finance and Support Services team dealt with 56 FTE in 2022.

- 86 k€, Collaborative Global Network for Rare Diseases by 3 companies

2.4. Foundations and Outside Health Sector Corporations

This section is composed of:

- Green Arrow Capital the alternatives platform, for 55k€ unrestricted.
- The support of the PHARI Fund, through a grant agreement with the Foundation Philanthropia Europe for a total amount of 200 k€ over two years to foster RDI's advocacy with the UN System was covering 2021 and 2022.
- The 176k€ of support from Chan Zuckerberg Initiative through an agreement with the Silicon Valley Community Foundation to support the Collaborative Global Network for Rare Diseases (CGN4RDs).

3. Expenses

3.1. Staff

At end 2022, the team was composed of 11 staff members across 6 countries, France (4), Belgium (2), Spain (1), Italy (2), Germany (1) and UK (1):

On EURORDIS' payroll and seconded to RDI

-1 permanent contract

- Flaminia Macchia: Executive Director (1 FTE)

On RDI' payroll

- 4 permanent contracts

- Hlawulani Mkhabela: Strategic Engagement Manager (1 FTE)
- Ayda Ramazzina: Governance & Development Manager (1 FTE)
- Mary Wang: Programme Manager (1FTE)
- Dolores Cvitičanin: Public Affairs Manager (1FTE)

- 2 temporary contracts

- Laura Philidor: Communications Junior Manager (0.9FTE)
- Nida Hasan: Global Capacity Building Junior Manager (0.5FTE)

- 4 regular part-time consultants on the Collaborative Global Network for Rare Diseases (CGN4RDs)

- Matt Johnson: Programme Director (0.6FTE)
- Concha Mayo: Programme Support Manager (0.6FTE)
- Veronica Lopez: Programme Manager (0.2FTE)
- Allison Watson: Programme Manager (0.2FTE)

3.2. Logistics

Increase of expenses this year 263K€ vs 47K€ in 2021 with the post Covid impact and return at a normal situation on travel and physical events.

100K€ mainly related to major events such as the World Health Assembly including the side event and RDI Global Gathering, the World Orphan Drug Congress, the Africa Rare Diseases Alliance meeting and Rare Disease Day.

In addition to that, an in-Kind of 116K€ coming from the biopharmaceutical company Alexion for the World Expo in Dubai on Rare Disease Day 2022

3.3. Services

Slightly higher in 2022 with a total 227 k€ this year, +6K€ variance vs. 2021 with main increase due to:

Decreasing Fees on the one hand (variance impact -13K€) with no Rare Barometer survey in 2022 mitigated by an increase of consultancy.

On the other hand, increasing in other services (variance +19K€) mainly due to higher participation in regional events in particular with the Asia Pacific Alliance of Rare Disease Organisations and the Ibero-American rare Diseases Alliance.

4. Result and Reserve

The result of 2022 is a surplus amounting to 43 €.

We suggest allocating it to the reserve which would increase to 340 791 € (an increase of 14%).

This reserve gives RDI the buffer it needs to compensate for the cash timing differences between income (irregular) and expenses (monthly, mainly work force).

This reserve represents 4 months of functioning (without in-kind) based on the budget 2023.