



RARE
DISEASES
INTERNATIONAL

FINANCIAL REPORT

2021



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INTERNATIONAL

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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, 2021

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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75014 PARIS

Statutory auditor's report on the financial statements

For the year ended December 31, 2021

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, 2021.

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, 2021 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, 2021 to the date of our report.

Justification of Assessments

Due to the global crisis related to the Covid-19 pandemic, the financial statements of this period have been prepared and audited under specific conditions. Indeed, this crisis and the exceptional measures taken in the context of the state of sanitary emergency have had numerous consequences for companies, particularly on their operations and their financing, and have led to greater uncertainties on their future prospects. Those measures, such as travel restrictions and remote working, have also had an impact on the companies' internal organization and the performance of the audits.

It is in this complex and evolving context that, 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 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 13, 2022

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY



Assets	2020	2021	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	100 050	459 171	359 121	359%
Account receivable due after one year	0	0	0	NA
Other receivables	6 263	9 440	3 177	
Liquid assets	103 847	431 529	327 682	316%
Prepaid expenses	549	449	-99	-18%
TOTAL	210 709	900 589	689 880	327%
Conversion adjustment	0	0	0	NA
TOTAL ASSETS	210 709	900 589	689 880	327%

Liabilities	2020	2021	Δ in euros	Δ in %
ASSOCIATION FUNDS				
Reserve	21 343	162 862	141 519	663%
Profit & loss for the year	141 519	134 974	-6 545	-5%
Subsidies of investment	0	0	0	NA
TOTAL	162 862	297 836	134 974	83%
Provisions for risk and charges	0	1 928	1 928	NA
Dedicated funds on grants	0	0	0	NA
DEBTS				
Bank loans and overdraft	0	0	0	NA
Trade creditors	18 860	125 412	106 552	565%
Tax payable and social liabilities	6 791	21 460	14 669	216%
Other debts	373	6 583	6 210	NA
Deferred income within one year	21 823	447 370	425 546	NA
Deferred income after one year	0	0	0	NA
TOTAL	47 847	602 752	554 906	NA
Conversion adjustment	0	0	0	NA
TOTAL LIABILITIES	210 709	900 589	689 880	327%



Revenue	2020 Fin. Status	2021 Fin. Status	Ratio
Patient Organisations	183 627	205 262	18%
In kind contributions (EURORDIS)	180 916	198 600	18%
Membership fees	2 712	6 662	1%
Individuals	176 623	307 311	27%
Volunteers	176 623	307 251	27%
Donations		60	0%
Corporates	332 036	510 868	45%
Pharma. and Biotech Companies	323 688	509 668	45%
Other Health Sector Corporates	8 349		
Outside Health Sector Corporates		1 200	0%
Not for Profit Organisations		100 000	9%
Pharma. and Biotech Found.			
Other Health Sector NPOs			
Outside Health Sector NPOs		100 000	9%
Miscellaneous	3	311	0%
Reimbursement			
Others	3	311	0%
Sub-total	692 290	1 123 752	100%
Recovery of provisions			
Report of non-used income			
Total Revenue	692 290	1 123 752	

Δ in euros	Δ in %
21 635	12%
17 685	10%
3 950	146%
130 688	74%
130 628	74%
60	
178 832	54%
185 980	57%
-8 349	
1 200	
100 000	
100 000	
309	
309	
431 463	62%
431 463	62%

Expenses	2020 Fin. Status	2021 Fin. Status	Ratio
Staff	297 958	405 220	41%
Wages and charges	184 584	282 256	29%
Other salaries	113 374	120 712	12%
Training and other costs		2 252	0%
Volunteers	176 623	307 251	31%
Representatives and task forces	174 706	297 863	30%
Projects, office and translators	1 918	9 388	1%
Logistics	10 682	47 338	5%
Travels and subsistence	7 030	37 338	4%
Event logistics and catering	172	10 000	1%
Virtual events	3 480		
Services	63 187	220 900	22%
Fees	54 119	218 520	22%
Partners			
Telecom and post	352	1 562	0%
Rent	8 349		
Other services	368	817	0%
Purchase	1 088	4 924	0%
Office furniture	610	1 203	0%
Communications, Publications	478	2 760	0%
Other purchases		960	0%
Miscellaneous	1 232	1 218	0%
Financial expenses, Insurance, Tax	1 232	1 218	0%
Exceptional expenses			
Sub-total	550 770	986 850	100%
Contingency and loss provisions		1 928	0%
Commitment on assigned income			
Total Expenses	550 770	988 778	
Result	141 519	134 974	

Δ in euros	Δ in %
107 262	36%
97 672	53%
7 338	6%
2 252	
130 628	74%
123 158	70%
7 470	390%
36 656	343%
30 309	431%
9 828	5706%
-3 480	
157 712	250%
164 401	304%
1 211	344%
-8 349	
449	122%
3 836	353%
593	97%
2 282	478%
960	
-14	-1%
-14	-1%
436 080	79%
1 928	
438 008	80%

1. Assets and Liabilities

The assets and liabilities of RDI amounted to 901 k€ at the end of 2021 compared to 211 k€ at the end of 2020.

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 (432 k€) and accounts receivable within one year (459 k€) in terms of assets, and mainly association funds (298 k€) and deferred income (447 k€) in terms of liabilities.

2. Income

In 2021, RDI's income came from three sources:

- Patient Organisations and Volunteers (46%)
- Donations from Pharmaceutical Companies (45%)
- Donations from Foundations - Outside Health Sector (9%)

2.1. Patient Organisations

Consists of membership fees (7 k€ in 2021 vs 3 k€ in 2020) and in-kind contribution from EURORDIS (198 k€ in 2021 vs 181 k€ in 2020, a 12% increase).

In 2021, out of 80 members, 43 paid their membership fees.

In 2021, EURORDIS provided the following in-kind contribution to support RDI:

- Staff (128 k€) consisting of the exact cost of the corresponding salaries and social charges for EURORDIS of:
 - o an Executive Director, Flaminia Macchia, full time (1 FTE)
 - o a Public Affairs Manager, Clara Hervas, part time 50% until end November 2021.
- the infrastructure (72 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 52¹ and multiplying it by the number of FTE at RDI. Our calculations showed a yearly cost of roughly 10 k€ per FTE + roughly 10 k€ for the website.

2.2. Volunteers

The economic value of volunteer's time is worth 307 K€ in 2021, an increase of +74% vs 2020.

All volunteers reported their time spent in 2021, validated by the Secretariat.

225 patient representatives, 1 advocate acting as RDI liaison to the United Nations in New York and 1 public health expert for the CGN4RDs, contributed to the mission of RDI totalling 4343 hours and corresponding to 2 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 all patient representatives at EURORDIS and RDI (65 €).

The advocates to the United Nations based in New York are valued at 250 \$ per hour.

Their hourly rate is in reality higher than this benchmark, but we wanted it to be as modest as possible in order to be sure that we do not over-estimate this non-cash resource.

¹ The Finance and Support Services team dealt with 52 FTE in 2021.

2.3. Pharmaceutical companies

In 2021, the donations received from that sector amounted to 510 k€ (vs 324 k€ in 2020 a +45% increase) broken down as followed:

- 240 k€, Alliance of Companies, by 12 companies 20 K€ each, unrestricted;
- 133 k€, Collaborative Global Network for Rare Diseases by 4 companies;
- 55 k€, Capacity Building Programmes;
- 60 k€, Rare Barometer Survey on Diagnosis;
- 20 k€, State of the Art.

2.4. Not for Profit Organisations

In 2021 RDI signed 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. It was particularly helpful in the context of the adoption of the Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families."

3. Expenses

3.1. Staff

As at the end of the year, the team was composed of 9 staff members, 4 full time on permanent contract, 2 full time on temporary contract, and 3 regular part-time consultants across 5 countries: France (4), Belgium (2), Spain (1), Italy (1) and Germany (1).

Four new positions were created in 2021 (in order of appearance):

- Ayda Ramazzina: Governance & Development Manager
- Nida Hasan: Global Capacity Building Junior Manager
- Mary Wang: Programme Manager
- Laura Philidor: Communications Junior Manager

In addition, three regular consultants were taken on in 2021:

- Matt Johnson: CGN4RD Programme Director
- Concha Mayo: CGN4RD Programme Support Manager
- Veronica Lopez: Programme Manager

3.2. Logistics

Given the pandemic situation, travel was on hold most of the time, but the team was able to gather for a strategic meeting in July and attend the World Orphan Drug Congress in November and the African Summit on Rare Diseases in Ghana in December.

3.3. Service Fees

The total amount of fees in 2021 was 219 k€.

It mainly consisted of:

- In-kind contribution from EURORDIS (71 k€)
- Rare Barometer Survey on Diagnosis (53 k€)
- Communications costs around the UN Resolution (32 k€)
- Consultancy on several topics, chartered accountant, auditors, etc.

4. Result and Reserve

The result of 2021 is a surplus amounting to 134 974 €.

We suggest allocating it to the reserve which would increase to 297 836 € (an increase of 83%).

This reserve gives RDI the buffer it needs to compensate for the cash timing differences between income (irregular) and expenses (monthly, mainly work force). RDI's social responsibilities are increasing with the recruitment of several new staff members in 2021 and 2022 and the development of its programmes.