



RARE  
DISEASES  
INTERNATIONAL

# FINANCIAL REPORT 2020

# RARE DISEASES INTERNATIONAL

Association governed by the French law of July 1, 1901

96, Rue Didot

75014 PARIS

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## Statutory auditor's report on the financial statements

For the year ended December 31, 2020

*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 shareholders.*

*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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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, 2020.

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, 2020 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, 2020 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 21, 2021

The Statutory Auditor

Deloitte & Associés

Jean-Claude MARTY

## 1. ASSETS AND LIABILITIES

The assets and liabilities of RDI amounted to 211 k€ at the end of 2020 compared to 39 k€ at the end of 2019.

As RDI has no fixed assets (such as computers, office furniture which are being provided by EURORDIS) and no pluriannual contract signed with a donor, the bulk of this amount consists of liquidities (104 k€) and accounts receivables within one year (100 k€) in terms of assets, and, mainly reserves (21 k€) and surplus of the year (142 k€) in terms of liabilities.

## 2. INCOME

In 2020, RDI's income comes from two main sources:

- Patient Organisations and Volunteers (52%)
- Donations from Pharmaceutical Companies (48%)

### 2.1. PATIENT ORGANISATIONS

Consists of membership fees (3 k€ in 2020 vs 1 k€ in 2019) and in kind contribution from EURORDIS (180 k€ in 2020 vs 134 k€ in 2019, a +26% increase).

In 2020, out of 76 members, only 19 paid their membership fees.

In 2020, EURORDIS provided the following in-kind contribution to support RDI:

- The staff (138 k€) consisting of the exact cost of the corresponding salaries and social charges for EURORDIS (138 k€):
  - > an Executive Director, Flaminia Macchia, full time (1 FTE)
  - > a Public Affairs Manager, Clara Hervas, part time (0.5 FTE)
- the infrastructure (43 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 website. The amount of this in kind contribution has been calculated by evaluating the cost for EURORDIS for all those activities, dividing it by 50<sup>1</sup> 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

All volunteers reported their time spent in 2019 and 2020, validated by the Secretariat.

70 patient representatives, 2 advocates 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 1825 hours and corresponding to 1 FTE.

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

Patient representatives and experts 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.

### 2.3. PHARMACEUTICAL COMPANIES

In 2020, the donations received from that sector amounted to 324 k€ (vs 180 k€ in 2019) dispatched as followed:

- 200 k€, Alliance of Companies, by 10 companies 20 K€ each, unrestricted;
- 80 k€, Collaborative Global Network for Rare Diseases;
- 30 k€, Programmes and Fellowships, rechannelled to salary costs with the approval of the donors due to the COVID situation;
- 14 k€, Unrestricted spontaneous donations.

### 2.4. OTHER HEALTH SECTOR CORPORATIONS

VOZ Advisors, a health sector consultant working for the pharmaceutical sector kindly offered EURORDIS an office space in New York. This in kind donation amounted to 8 k€ in

2020 vs 41 k€ in 2019, as the offices was made available only until the pandemic spurred.

## 3. EXPENSES

### 3.1. STAFF

In 2020, RDI Secretariat was composed of six staff:

- On RDI's payroll, one full time employee since March 2020, Hlawulani Mkhabela, Outreach and Engagement Manager (1 FTE);
- On EURORDIS' payroll and seconded to RDI: Flaminia Macchia, Executive Director, (1 FTE) and Clara Hervas, Public Affairs Manager (0.5 FTE);
- Two consultants contracted to work on the WHO Collaborative Global Network for Rare Diseases (CGN4RDs), Matt Bolz-Johnson, Programme Director – CGN4RDs (0.6 FTE) and Concha Mayo, Programme Manager – CGN4RDs (0.4 FTE);
- One consultant contracted as Corporate Resources Director, Jill Bonjean (0.3 FTE)

### 3.2. LOGISTICS

Given the pandemic situation, travel has been on hold.

### 3.3. FEES

The bulk of this section is the in-kind donation of the management of RDI's overheads by EURORDIS which would have to externalise its accounting, payroll, IT and website management (43 k€). The remaining 10 K€ are the fees for legal advice to review contracts, the chartered accountant, the annual account auditing by Deloitte.



## 4. RESULT AND RESERVE

The result of 2019 is a surplus amounting to 21 343 €.

We have allocated it to the reserve in the accounts in anticipation of the resolution that will be voted today.

The result of 2020 amounted to 141 519 €.

We suggest allocating it to the reserve which would increase to 162 862 €.

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 social responsibilities are increasing with the recruitment of two new staff members in 2021 and the development of its programmes.


**RDI 2020 Financial Status**  
 (Assets and Liabilities)

Assets	2019	2020	Δ in euros	Δ in %
<b>FIXED ASSETS</b>				
Intangible assets	0	0	0	NA
Tangible assets	0	0	0	NA
Financial assets	0	0	0	NA
<b>TOTAL</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>NA</b>
<b>CURRENT ASSETS</b>				
Account receivable due within one year	800	100 050	99 250	NA
Account receivable due after one year	0	0	0	NA
Other receivables	0	6 263	6 263	
Liquid assets	37 829	103 847	66 019	175%
Prepaid expenses	0	549	549	NA
<b>TOTAL</b>	<b>38 629</b>	<b>210 709</b>	<b>172 080</b>	<b>445%</b>
<b>Conversion adjustment</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>NA</b>
<b>TOTAL ASSETS</b>	<b>38 629</b>	<b>210 709</b>	<b>172 080</b>	<b>445%</b>

Liabilities	2019	2020	Δ in euros	Δ in %
<b>ASSOCIATION FUNDS</b>				
Reserve	0	21 343	21 343	NA
Profit & loss for the year	21 343	141 519	120 176	563%
Subsidies of investment	0	0	0	NA
<b>TOTAL</b>	<b>21 343</b>	<b>162 862</b>	<b>141 519</b>	<b>663%</b>
Provisions for risk and charges	0	0	0	NA
Dedicated funds on grants	0	0	0	NA
<b>DEBTS</b>				
Bank loans and overdraft	0	0	0	NA
Trade creditors	10 250	18 860	8 610	84%
Tax payable and social liabilities	0	6 791	6 791	NA
Other debts	6 835	373	-6 463	-95%
Deferred income within one year	200	21 823	21 623	NA
Deferred income after one year	0	0	0	NA
<b>TOTAL</b>	<b>17 286</b>	<b>47 847</b>	<b>30 561</b>	<b>177%</b>
<b>Conversion adjustment</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>NA</b>
<b>TOTAL LIABILITIES</b>	<b>38 629</b>	<b>210 709</b>	<b>172 080</b>	<b>445%</b>

**2020 Financial Status  
VS 2019 Financial Status**  
(Profit and Loss including in kind contributions)

Revenue	2019 Fin. Status	2020 Fin. Status	Ratio	Δ in euros	Δ in %
<b>Patient Organisations</b>	<b>134 965</b>	<b>183 627</b>	<b>27%</b>	<b>48 662</b>	<b>36%</b>
In kind contributions (EURORDIS)	133 965	180 916	26%	46 951	35%
Membership fees	1 000	2 712	0%	1 712	171%
<b>Individuals</b>	<b>143 215</b>	<b>176 623</b>	<b>26%</b>	<b>33 408</b>	<b>23%</b>
Volunteers	143 195	176 623	26%	33 428	23%
Donations	20			-20	
<b>Corporates</b>	<b>241 235</b>	<b>332 036</b>	<b>48%</b>	<b>90 802</b>	<b>38%</b>
Pharma. and Biotech Companies	180 000	323 688	47%	143 688	80%
Other Health Sector Corporates	61 235	8 349	1%	-52 886	-86%
Outside Health Sector Corporates					
<b>Not for Profit Organisations</b>					
Pharma. and Biotech Found.					
Other Health Sector NPOs					
Outside Health Sector NPOs					
<b>Miscellaneous</b>	<b>15 006</b>	<b>3</b>	<b>0%</b>	<b>-15 004</b>	<b>-100%</b>
Reimbursement	15 000			-15 000	
Others	6	3	0%	-4	-58%
<b>Sub-total</b>	<b>534 421</b>	<b>692 290</b>	<b>100%</b>	<b>157 869</b>	<b>30%</b>
<b>Recovery of provisions</b>					
<b>Report of non-used income</b>					
<b>Total Revenue</b>	<b>534 421</b>	<b>692 290</b>		<b>157 869</b>	<b>30%</b>

Expenses	2019 Fin. Status	2020 Fin. Status	Ratio	Δ in euros	Δ in %
<b>Staff</b>	<b>157 975</b>	<b>297 958</b>	<b>54%</b>	<b>139 982</b>	<b>89%</b>
Wages and charges	107 675	184 584	34%	76 909	71%
Other salaries	50 300	113 374	21%	63 074	125%
Training and other costs					
<b>Volunteers</b>	<b>143 195</b>	<b>176 623</b>	<b>32%</b>	<b>33 428</b>	<b>23%</b>
Representatives and task forces	143 195	174 706	32%	31 511	22%
Projects, office and translators		1 918	0%	1 918	
<b>Logistics</b>	<b>106 094</b>	<b>10 682</b>	<b>2%</b>	<b>-95 412</b>	<b>-90%</b>
Travels and subsistence	97 337	7 030	1%	-90 307	-93%
Event logistics and catering	8 757	172	0%	-8 585	-98%
Virtual events		3 480	1%	3 480	
<b>Services</b>	<b>96 956</b>	<b>63 187</b>	<b>11%</b>	<b>-33 769</b>	<b>-35%</b>
Fees	33 087	54 119	10%	21 032	64%
Partners	20 000			-20 000	
Telecom and post	1 620	352	0%	-1 269	-78%
Rent	41 235	8 349	2%	-32 886	-80%
Other services	1 014	368	0%	-647	-64%
<b>Purchase</b>	<b>6 683</b>	<b>1 088</b>	<b>0%</b>	<b>-5 595</b>	<b>-84%</b>
Office furniture	116	610	0%	495	428%
Communications, Publications	6 427	478	0%	-5 950	-93%
Other purchases	140			-140	
<b>Miscellaneous</b>	<b>2 175</b>	<b>1 232</b>	<b>0%</b>	<b>-943</b>	<b>-43%</b>
Financial expenses, Insurance, Tax	2 175	1 232	0%	-943	-43%
Exceptional expenses					
<b>Sub-total</b>	<b>513 078</b>	<b>550 770</b>	<b>100%</b>	<b>37 692</b>	<b>7%</b>
<b>Contingency and loss provisions</b>					
<b>Commitment on assigned income</b>					
<b>Total Expenses</b>	<b>513 078</b>	<b>550 770</b>		<b>37 692</b>	<b>7%</b>
<b>Result</b>	<b>21 343</b>	<b>141 519</b>			



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