

FOREWORD FROM THE CEO

2024: A YEAR OF CONSOLIDATION AND STRATEGIC INVESTMENTS

RDI's 2024 financial accounts and report were prepared by RDI Finance & Administration Manager Marco Pasetti together with our Chartered Accountant Actheos, audited by Deloitte & Associates in March and April 2025.

Deloitte performed an ordinary audit of the financial statements (balance sheet, income statement, and notes). The financial statements provide a true and fair view of the assets, liabilities, and financial position of the Association as of December 31, 2024, as well as the results of its operations for the year then ended, in accordance with French accounting principles.

2024 was a year of transformation for RDI, marking our first full year of financial and operational independence following the conclusion of the Memorandum of Understanding with EURORDIS. This transition required key investments in internal capacity, including the full integration of our staff, ensuring that RDI operates with a dedicated and self-sufficient team. Additionally, we conducted an organisational review, an important step to strengthen our structure and processes. While this is reflected in our 2024 expenditures, it is a long-term investment that will drive efficiency and strategic growth in the years ahead.

Financially, RDI navigated a moderate deficit, mainly due to these strategic investments, the resolution of some unexpected administrative costs, and the absence of an important funding source we had initially anticipated. However, thanks to careful financial management and cost controlling, we effectively mitigated the impact, maintaining a strong reserve and financial stability.

In 2024, total income amounted to 1.150 k€, a decrease of 55 k€ compared to 2023, while expenditures reached 1.242 k€, reflecting the increased activities and the organizational growth. Revenue diversification remained a key priority, with 57% of funding from Healthcare Companies, 15% from Non-Healthcare Organisations, 24 % from Volunteers and Patient Organisations, and 3% from Horizon Europe (ERDERA), marking the first ever Institutional Funding in RDI's history.

Despite the financial challenges of 2024, RDI is on a solid path forward. The steps taken this year were essential to reinforce our autonomy, strengthen our team, and build a more resilient organization. Looking ahead to 2025, we are confident that these strategic choices will enable us to expand our impact, develop our programs, and further support the rare disease community worldwide.



ALEXANDRA HEUMBER PERRY
CHIEF EXECUTIVE OFFICER

RDI 2024 FINANCIAL STATUS

BALANCE SHEET

ASSETS	2024 EUR	2023 EUR	Δ
Intangible Fixed Assets	-	-	-
Tangible Assets	3 104	-	3 104
Trade notes & accounts receivable	72 733	35 137	37 596
Others receivable	16 016	-	16 016
Prepaid Expenses	109	-	109
Cash - Current Accounts	618 119	662 620	- 44 500
TOTAL ASSETS	710 082	697 757	- 4 424

LIABILITIES	2024 EUR	2023 EUR	Δ
Reserve	610 253	340 791	269 462
Profit/Loss for the period	- 91 795	269 463	- 361 257
Provisions for loss	432	432	-
Accounts payables	20 408	48 058	- 27 650
Other Debts & accruals liabilities	40 783	39 014	1 769
Deferred income	130 000	-	130 000
TOTAL LIABILITIES	710 082	697 757	12 325

PROFIT AND LOSS (WITH IN-KIND CONTRIBUTIONS)

INCOME		2024 EUR	2023 EUR	Δ
Patient Organizations		12 350	72 159	- 59 809
	Membership fees	12 350	7 000	5 350
	Eurordis In-Kind contribution	-	65 159	-65 159
Volunteers		262 604	181 611	80 993
	Donations	136	987	-851
	In Kind Services	262 468	180 624	81 844
Healthcare Companies		654 313	574 108	80 205
	Pharma. and Biotech Companies	654 313	574 108	80 205
Non-Healthcare Organizations		167 000	363 697	- 196 697
	Outside Health Sector Corporates		75 000	- 75 000
	Outside Health Sector NPOs	167 000	288 697	- 121 697
Institutional Fundings		33 930	-	33 930
Miscellaneous		19 513	13 434	6 079
	Reimbursement	5 040	9 537	- 4 497
	Others	14 473	3 896	10 577
TOTAL INCOME		1 149 710	1 205 009	- 55 299
EXPENSES		2024 EUR	2023 EUR	Δ
Staff		581 961	480 587	101 374
	Wages and charges	368 737	289 077	79 661
	Other salaries	213 096	123 874	89 222
	Training and other costs	128	2 477	- 2 350
	Eurordis In-Kind Contribution	-	65 159	- 65 159
Logistics		485 619	319 207	166 412
	Travels and subsistence	214 733	126 549	88 184
	Event logistics and catering	8 418	12 033	- 3 616
	In Kind services	262 468	180 624	81 844
Services		108 639	127 024	- 18 384
	Fees	90 883	99 095	- 8 213
	Reg Conf Partners	2 000	14 000	- 12 000
	Telecom and post	2 418	3 244	- 826
	Other services	13 339	10 684	2 654
Purchase		8 801	3 706	5 095
	Office furniture	4 638	2 635	2 003
	Other purchases	4 163	1 072	3 092
Miscellaneous		56 484	5 023	51 462
	Financial expenses, Insurance, Tax	8 761	5 023	3 738
	Contingency & Legal Settlements	47 724		
TOTAL EXPENSES		1 241 505	935 546	305 958
RESULT		- 91 795	269 463	- 361 258

1. ASSETS

- **Tangible Assets:** The acquisition of tangible assets for 3 k€ reflects an investment in equipment necessary for operations, specifically computers.
- **Trade Notes & Accounts Receivable:** The significant increase of 37 k€ compared to 2023 is largely due to outstanding payments related to agreements signed at the end of the period.
- **Cash - Current Accounts:** The decrease of 44.5 k€ in cash reserves indicates a moderate use of liquidity, reflecting operational activities and investments

2. LIABILITIES

- **Reserve:** The increase of 270 k€ in reserves primarily reflects the carryover of last year's surplus, reinforcing the financial stability of the association. This growth in reserves is a positive indicator, demonstrating good resource management and providing a solid foundation to handle uncertainties or invest in future initiatives.
- **Profit/Loss for the Period:** The transition from a surplus of 270 k€ in 2023 to a deficit of 92 k€ in 2024 reflects the challenges faced during the year, as outlined in the foreword from the CEO.
- **Accounts Payables:** The significant decrease in accounts payable (from 48 k€ to 20 k€) suggests that RDI has effectively reduced its debts to suppliers, demonstrating strong liability management and contributing to overall financial stability. Payments to suppliers have been consistently made on time.
- **Deferred income:** The 130 k€ in deferred income corresponds to agreements signed in 2024 that pertain to the following period.

3. BALANCE SHEET SUMMARY

The overall financial situation demonstrates strong management, highlighted by an increase in reserves and a reduction in accounts payable. While the 2024 result reflects a deficit compared to the surplus in 2023, RDI remains in a solid financial position, with strategic measures in place to stabilize and ensure future growth, reinforcing the association's longterm sustainability.

INCOME

In 2024, RDI's incomes mainly came from three key sources:

- Patient Organisations and Volunteers (23%)
- Donations from Foundations and Outside Health Sector Corporations (15%)
- Donations from Health sector Companies (58%)

RDI also received 3% from institutional funding through Horizon Europe (ERDERA project) marking an important step towards diversification. This grant, the first of its kind for RDI, demonstrates the organization's ability to secure funding from new and varied sources.

1. Patient Organizations

The drop of 60 k€ (from 72 k€ in 2023 to 12.5k€ in 2024) is mainly due to the absence of the Eurordis In-Kind Contribution, which amounted to 65 k€ in 2023, following the end of the MoU. It's important to highlight the substantial increase (+76%) in membership fees which, while relatively small in financial terms, represents a significant boost in community engagement. This increase is a testament to the dedication of both the community and the finance team in strengthening RDI's ties with its members and ensuring their continued support.

2. Volunteers

The economic value of volunteer's time is worth 263 K€ in 2024.

The significant increase in in-kind services (+81 k€ compared to 2023) reflects a strong level of volunteer engagement, which continues to be a vital part of RDI's operations. This increase can also be attributed to cross-cutting projects such as the Lancet Commission, the WHA Resolution Task Force, and the Essential Medicine List. These projects have not only fostered greater volunteer involvement but have also showcased the power of collaboration in driving forward the mission of RDI.

3. Healthcare Companies

In 2024, financial contributions from the healthcare sector amounted to 654 k€ distributed as follows:

- 450 k€ - Alliance of Companies (with 15 companies contributing 30 k€ each)
- 125 k€ - Strategic Engagement Programmes
- 80 k€ - Global Network Programmes

This represents an increase of 80 k€ compared to 2023, reflecting consistent support from this sector. This positive trend highlights the continued relevance and engagement of these partners in RDI's mission.

4. Non-Healthcare Organizations

In 2024, financial contributions from this sector amounted to 167 k€, composed of:

- 100 k€ - Support from the Fondation de Luxembourg, through a grant agreement with the Foundation Philanthropia Europe, to support the Lancet Commission on Rare Diseases.
- 45 k€ - Support from the IPSEN Foundation, through an agreement with the Fondation de France, to support the Youth Leadership Programme.
- 22 k€ - Support from IFPMA (20 k€) and Premier Research (2 k€) for various activities

This represents a decrease of 197 k€ compared to 2023, primarily due to shifts in funding priorities among one key donor. This has impacted RDI's diversification efforts for 2024, so a strong and targeted strategy is currently underway to strengthen income diversification and open up new collaboration opportunities.

5. Institutional Funding

In 2024, RDI received 33.9 k€ from the European Community, marking a significant milestone as the first institutional funding for the organization. This funding, related to the multi-year ERDERA project, represents the allocation for 2024 and highlights a promising new area for expansion and diversification of RDI's income sources in the future.

6. Miscellaneous

This section mainly includes currency exchange gains and other accounting and financial revenues/adjustments, with a modest increase of 6 k€ driven by reimbursements and other small incomes.

Income Summary

Despite the removal of the Eurordis In-Kind Contribution, and the temporary loss of a key donor, the decrease in total income remained slight (down by 55 k€ from 1.205 k€ in 2023 to 1.150 k€ in 2024). This is largely due to the growth in other income areas, such as membership fees, Healthcare sector, and Institutional funding, which helped mitigate the overall reduction.

EXPENSES

1. Staff

In 2024, staff costs amounted to 582 k€, with an increase of 101 k€ compared to 2023. This rise is primarily due to the internalization of some positions following the removal of the Eurordis In-Kind Contribution. As a result, some roles previously covered by external support have now been brought in-house, contributing to a more financially demanding structure. This increase also reflects new hires and the strengthening of the team, which is now better equipped to meet RDI's growing needs.

At end 2024, the RDI whole team was composed of 9 internal staff members (including the CEO seconded by The Business Harbour) across 3 countries: France, Italy, and Switzerland.

RDI staff have been structured in 4 different departments:

- **Administration:** CEO – Finance & Administration Manager – Senior Executive Assistant
- **Global Programme:** Global Programme Director – Junior Global Programme Manager – Global Programme Trainee
- **Strategic Engagement:** Strategic Engagement Manager – Communication Assistant
- **Advocacy:** Global Policy coordinator

This structured team is now fully equipped to support RDI's strategic objectives and operational needs, ensuring efficient use of resources as the organization moves forward.

2. Logistics

In 2024, logistics costs amounted to 486 k€, reflecting a substantial increase of 166 k€ compared to 2023. This increase is primarily driven by travel and subsistence costs (88 k€) and in-kind services (82 k€). The rise in expenses is aligned with the organization's expanded activities. Notably, RDI organized and attended several events in 2024. This included the World Health Assembly (WHA) in May, where RDI also organized a successful side event, as well as the RDI Membership Meeting held in Barcelona on October during the WODC week, which involved significant logistical coordination and expenditures for inviting RDI members. Furthermore, the organization's increased staff and membership base has contributed to a higher demand for logistical operations.

Despite these increases, RDI has implemented internal policies and leveraged centralized booking platforms to effectively manage and control logistics costs. These measures have helped maintain operational efficiency and mitigate excessive spending while supporting the organization's growing activities.

3. Services

In 2024, services costs amounted to 109 k€, showing a decrease of 18 k€ compared to 2023. This reduction highlights significant cost-control efforts despite the inclusion of 40 k€ in fees related to the organizational review. The services category includes essential consultancy costs, including accountancy, legal services, HR, and IT support, all of which have been managed effectively to keep overall expenses down. This cost-saving trend demonstrates RDI's commitment to optimizing its resources while maintaining high-quality support for its operations.

4. Purchase

Purchase costs amount to 9 k€ (up 5 k€ compared to 2023) reflect additional investments in office furniture and other operational supplies, although they are not significant in total.

5. Miscellaneous

In 2024 miscellaneous expenses amounted to 56 k€, with a significant increase of 51 k€ compared to 2023, primarily driven by settlements related to employee disputes (48 k€). These costs stem from legal cases that were resolved during the year. With these cases now behind, RDI has strengthened its internal processes and capabilities, reducing the likelihood of encountering similar issues in the future.

Expense Summary

The rise in total expenses, which increased by 306 k€ from 937 k€ in 2023 to 1.242 k€ in 2024, was driven by necessary investments in expanding staff and enhancing organizational activities. These increases were partially offset by cost-control measures in other areas, allowing the organization to effectively manage the growth while supporting its expanded scope and operational needs.

RESULT AND NET WORTH

The financial result for 2024 shows a deficit of 92 k€. However, the association's net worth stands at 518 k€, providing a crucial buffer to cover cash flow timing differences between income (which can be irregular) and expenses (which are primarily monthly and driven by workforce costs).

This reserve represents approximately six months of operations (excluding in-kind contributions) based on the 2025 budget, enabling RDI to continue developing its programs and supporting its growing organizational structure.

TRANSPARENCY AND FINANCIAL ACCOUNTABILITY

RDI is dedicated to maintaining high standards of financial transparency and accountability. In 2024, we continued to prioritize open communication with our stakeholders by:

- **Ensuring Clarity in Financial Reporting:** We strive to provide clear, accurate, and accessible financial information, enabling our donors and partners to track how funds are utilized and the impact of their contributions.
- **Strengthening Internal Governance:** We have reinforced our internal governance structure, implementing measures to improve the oversight of our financial operations, ensuring responsible management of resources. These efforts aim to uphold trust with our stakeholders and demonstrate our commitment to efficient and responsible financial management

CONCLUSIONS

Despite the deficit reported in 2024, RDI is focused on implementing strategies to restore financial stability in the coming years. Key priorities will include optimizing revenue through further diversification of funding sources, strengthening existing partnerships, and exploring new opportunities for collaboration with donors and institutions. We will manage our reserve fund prudently to ensure continued operations, while focusing on enhancing our team's capacity. This approach will help us address future challenges, maintaining a balance between cost control and sustainable growth.