

FINANCIAL INDEPENDENCE FORM

A - Core income/funding in year n (2)

Funding from Private sector

Full Name and Address of the Donor	Branch of activity	Purpose (3)	Amount
AFM	Patient Organisations	Core activities grant	634 500
AFM	Patient Organisations	Renting in kind	196 053
Individual Donors	Not Applicable	Unrestricted	42 158
Volunteers	Patient Organisations	Advocacy	1 308 943
Corporate Donors	Pharma. Comp.	ERTC unrestricted	472 000
Corporate Donors	Health Sector	ERTC unrestricted	10 000
			2 663 654

Funding from Public sector

Full Name and Address of the Donor	Branch of activity	Purpose (3)	Amount
CHAFAEA	Health and Food	Operating Grant	1 027 785
EMA	Health	In kind (attendance)	46 223
			1 074 008

TOTAL CORE INCOME in Year N:

3 737 662

B - Non core income (project funding) in year n

Funding from Private sector

Full Name and Address of the Donor	Branch of activity	Purpose	Amount
Patient Organisations	Repr. of civil society	Com. Advisory Boards	49 000
Corporate Donors	Pharma. Comp.	European Conf. on Rare Dis.	245 000
Corporate Donors	Pharma. Comp.	ERTC restricted	85 000
Corporate Donors	Pharma. Comp.	International Initiatives	247 981
Corporate Donors	Pharma. Comp.	Rare Impact	168 000
Corporate Donors	Pharma. Comp.	Black Pearl Awards	200 000
Corporate Donors	Pharma. Comp.	Rare Diseases International	80 000
Corporate Donors	Pharma. Comp.	Rare Barometer	75 000
Corporate Donors	Pharma. Comp.	Web2.0 - Rare Connect	90 000
Corporate Donors	Health Sector	ERTC restricted	40 000
Corporate Donors	Health Sector	Black Pearl Awards	20 000
Media Planet	Media exposure	Rare Disease Day	21 282
Financial Times	Media	Rare Disease Day	57 803
Google Adwords	Internet	RareConnect	4 096
Publicis Lifebrand	Marketing	Rare Disease Day	25 375
Ass. of Int. Pharm. Man.	Pharm. Syndicate (RU)	EURORDIS Int. Initiatives	20 000
EveryLife Foundation	Health NPO	Black Pearl Awards	10 000
CHEO	Health Care	RareConnect	72 718
Bertarelli Foundation	Non Health NPO	Black Pearl Awards	10 000
Kindness for Kids	Foundation	InnovCare	5 000
			1 526 255

Funding from Public sector

Full Name and Address of the Donor	Branch of activity	Purpose	Amount
DG Research	Research	connect4children	17 924
DG Research	Research	RD-CONNECT	55 667
DG Research	Research	PARADIGM	73 111
DG Research	Research	Solv-RD	146 251
DG SANTE	Health and Food	Rare Cancers Joint Action	39 364
DG SANTE	Health and Food	RD-ACTION	37 190
DG EMPLOYMENT	Employment	InnovCare	223 300
ANR - E-Rare3	Research	E-Rare3	11 400
CIHR	Research	Summer School	4 500
			608 706

TOTAL NON CORE INCOME in Year N:

2 134 962

C - Other operating income in year n

Source	Amount
Membership and subscriptions	59 595
Conferences & workshop fees	333 829
Sale of publications	
Other	128 294

TOTAL OTHER INCOME in YEAR N:

521 718

TOTAL INCOME in YEAR N:

6 394 342

Patrice Régnier, Finance and Support
Services Unit Director
Paris, February 22nd 2019



- (1) In order to be considered independent, applicant organisations must unilaterally commit not to receive more than 20 % of their core funding from private sector organisations representing a conflicting interest, or from other sources representing a conflicting interest during the financial years covered by the grant. The term 'private sector' covers 'for-profit' companies/enterprises/corporations, business organisations or other entities irrespective of their legal nature (registered/not registered), ownership (wholly or partially privately owned/state owned) or size (large/small), if they are not controlled by the public
- (2) Core funding shall mean financing required for the basic structure of an organization, including salaries of full-time staff, facilities, equipment, communications, and the direct expenses of day-to-day work. Core funding also includes financing of all permanent or regularly repeated activities. Core funding requirements are often budgeted separately from other costs like specific actions or projects
- (3) Please specify according to the description of "core funding" given above