

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	172 746
AFM	Patient Organisations	Video in kind	40 000
Individual Donors	Not Applicable	Unrestricted	12 411
Volunteers	Patient Organisations	Advocacy	1 113 885
Corporate Donors	Pharma. Comp.	ERTC	457 000
Corporate Donors	Health Sector	ERTC	50 000
Corporate Donors	Health Sector	Intercept	2 000
Multiburo	Office renting	Renting in kind	10 512
Burson Marsteller	Communications	Services in kind	3 747
DLA PIPER	Lawyer	Services in kind	44 782
			2 541 583

Funding from Public sector

Full Name and Address of the Donor	Branch of activity	Purpose (3)	Amount
CHAFEA	Health and Food	Operating Grant	792 021
EMA	Health	EMA secondment	98 745
EMA	Health	In kind (attendance)	68 285
			959 051

TOTAL CORE INCOME in Year N:	3 500 634
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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
Members	Members	Rare Diseases International	54 946
Corporate Donors	Pharma. Comp.	Web2.0 - Rare Connect	85 000
Corporate Donors	Pharma. Comp.	EURORDIS Gala Dinner	385 000
Corporate Donors	Pharma. Comp.	Eurordis Memb. Meet.	175 000
Corporate Donors	Pharma. Comp.	ERTC Symposium	70 000
Corporate Donors	Pharma. Comp.	Rare Barometer	82 841
Corporate Donors	Pharma. Comp.	International Initiatives	72 000
Corporate Donors	Pharma. Comp.	Rare Diseases International	114 790
IDIS Pharma	Health Sector Corp.	EURORDIS Gala Dinner	10 000
Krueger & Associates	Health Sector Corp.	EURORDIS Gala Dinner	3 000
Ares Life Science	Investors	EURORDIS Gala Dinner	8 000
Fundatio San Pau	Foundation	Barcelona Platform	79 854
Kindness for Kids	Foundation	InnovCare	5 000
EFPIA	Pharm. Syndicate (EU)	IMI-JU EUPATI co-funding	97 780
EveryLife Foundation for R	Health Foundation	EURORDIS Gala Dinner	10 000
Media Planet	Media exposure	Rare Disease Day	5 650
Google Adwords	Internet	RareConnect	109 185
Trommons	In Kind Translations	RareConnect	5 247
Translators without borders	In Kind Translations	RareConnect	2 733
Individuals	In Kind Translations	RareConnect	158
Interactius	IT Agency	RareConnect	4 480
Publicis Lifebrand	Marketing	Rare Disease Day	11 700
Redmond Consulting	Consulting	Rare Disease Day	2 936
Mapi	Health Sector Corp.	Rare Barometer	27 812
Novartis	Pharma. Comp.	Faculty member fee	500
Ass. of Int. Pharm. Man.	Pharm. Syndicate (RU)	e-newsletter	25 000
			1 448 612

Funding from Public sector

Full Name and Address of the Donor	Branch of activity	Purpose	Amount
DG Research	Research	RD-CONNECT	101 422
DG Research	Research	Genetic Clinic Of the Fut.	37 898
DG Research	Research	Rare Best Practices	47 228
DG Research	Research	COST - In Kind	14 430
IMI-JU	Research	EUPATI	160 925
IMI-JU	Research	Web-Radr	29 472
IMI-JU	Research	Adapt Smart	30 333
DG SANTE	Health and Food	RD-ACTION	231 236
DG SANTE	Health and Food	PACE ERN	51 916
DG SANTE	Health and Food	Rare Cancers Joint Action	3 565
DG EMPLOYMENT	Employment	InnovCare	199 985
Visit Scotland	Edinburgh	ECRD 2016	17 877
Marketing Edinburgh	Edinburgh	ECRD 2016	19 390
ANR - E-Rare3	Research	E-Rare3	21 090
			966 768

TOTAL NON CORE INCOME in Year N:	2 415 380
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C - Other operating income in year n

Source	Amount
Membership and subscriptions	48 275
Conferences & workshop fees	252 316
Sale of publications	
Other	95 578

TOTAL OTHER INCOME in YEAR N:	396 169
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TOTAL INCOME in YEAR N:	6 312 183
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Patrice Régner, Finance and Support Services
Unit Director
Paris, February 22nd 2017



- (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

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Company	Purpose	Amount
ACHILLION	Round Table of Companies	10 000
ACTELION	Round Table of Companies	10 000
AKCEA	Round Table of Companies	10 000
ALEXION	Round Table of Companies	10 000
ALNYLAM	Round Table of Companies	25 000
AMGEN	Round Table of Companies	5 000
AMICUS THERAPEUTICS	Round Table of Companies	5 000
ASTRAZENECA	Round Table of Companies	10 000
AUDENTES	Round Table of Companies	10 000
BAXALTA	Round Table of Companies	10 000
BAYER	Round Table of Companies	5 000
BIOGEN	Round Table of Companies	10 000
BIOMARIN	Round Table of Companies	10 000
BLUEBIRD BIO	Round Table of Companies	10 000
BOEHRINGER INGELHEIM	Round Table of Companies	10 000
BRISTOL-MYERS SQUIBB	Round Table of Companies	10 000
CELGENE	Round Table of Companies	25 000
CHIESI	Round Table of Companies	5 000
CSL BEHRING	Round Table of Companies	10 000
CYTOKINETICS	Round Table of Companies	10 000
DOMPE	Round Table of Companies	5 000
EUSA PHARMA	Round Table of Companies	10 000
GENZYME	Round Table of Companies	25 000
GRIFOLS	Round Table of Companies	10 000
HORIZON	Round Table of Companies	5 000
INCYTE	Round Table of Companies	10 000
INSMED	Round Table of Companies	5 000
LFB BIOMEDICAMENTS	Round Table of Companies	10 000
LYSOGENE	Round Table of Companies	2 000
MERCK	Round Table of Companies	10 000
NOVARTIS	Round Table of Companies	10 000
ORPHAN EUROPE	Round Table of Companies	10 000
OVID	Round Table of Companies	5 000
PHARMA MAR	Round Table of Companies	5 000
PTC	Round Table of Companies	10 000
RAPTOR	Round Table of Companies	10 000
ROCHE	Round Table of Companies	10 000
SANTHERA	Round Table of Companies	10 000
SHIRE	Round Table of Companies	25 000
SIGMA-TAU	Round Table of Companies	5 000
SOBI	Round Table of Companies	10 000
SPARK THERAPEUTICS	Round Table of Companies	5 000
TAKEDA	Round Table of Companies	5 000
UCB	Round Table of Companies	5 000
ULTRAGENYX	Round Table of Companies	10 000
VANDA	Round Table of Companies	10 000
VERTEX	Round Table of Companies	10 000
	Round Table of Companies Total	457 000
BIOMARIN	ERTC Symposium	5 000

CELGENE	ERTC Symposium	5 000
CSL BEHRING	ERTC Symposium	20 000
PFIZER	ERTC Symposium	40 000
	ERTC Symposium Total	70 000
ACTELION	Gala Dinner (even)	35 000
AMICUS THERAPEUTICS	Gala Dinner (even)	10 000
ARIAD	Gala Dinner (even)	4 615
BAYER	Gala Dinner (even)	35 000
BIOGEN	Gala Dinner (even)	25 000
BIOMARIN	Gala Dinner (even)	25 000
CELGENE	Gala Dinner (even)	25 000
CHIESI	Gala Dinner (even)	10 000
CLEMENTIA	Gala Dinner (even)	10 000
CSL BEHRING	Gala Dinner (even)	11 538
CYTOKINETICS	Gala Dinner (even)	20 000
HORIZON	Gala Dinner (even)	15 000
ORPHAN EUROPE	Gala Dinner (even)	10 000
PTC	Gala Dinner (even)	25 000
RAPTOR	Gala Dinner (even)	10 000
SANTHERA	Gala Dinner (even)	5 000
SHIRE	Gala Dinner (even)	50 000
SIGMA-TAU	Gala Dinner (even)	4 615
SOBI	Gala Dinner (even)	10 000
ULTRAGENYX	Gala Dinner (even)	9 231
	Gala Dinner (even) Total	350 000
CSL BEHRING	Gala Dinner (odd)	14 000
HORIZON	Gala Dinner (odd)	14 000
SIGMA-TAU	Gala Dinner (odd)	7 000
	Gala Dinner (odd) Total	35 000
ALEXION	EMM	10 000
BIOMARIN	EMM	10 000
CHIESI	EMM	10 000
CSL BEHRING	EMM	15 000
GENZYME	EMM	10 000
IPSEN	EMM	15 000
KYOWA KIRIN	EMM	15 000
NOVARTIS	EMM	10 000
ORPHAN EUROPE	EMM	10 000
PFIZER	EMM	25 000
RAPTOR	EMM	10 000
SHIRE	EMM	25 000
SOBI	EMM	10 000
	EMM Total	175 000
CHIESI	RareConnect	15 000
GSK	RareConnect	35 000
NOVARTIS	RareConnect	20 000
RAPTOR	RareConnect	15 000
	RareConnect Total	85 000
GSK	RareBarometer	35 000
TAKEDA	RareBarometer	32 841

VERTEX	RareBarometer	15 000
	RareBarometer Total	82 841
BIOGEN	RareDiseasesInternational	15 623
GENZYME	RareDiseasesInternational	20 000
NOVARTIS	RareDiseasesInternational	39 167
SHIRE	RareDiseasesInternational	20 000
VERTEX	RareDiseasesInternational	20 000
	RareDiseasesInternational Total	114 790
CELGENE	EURORDIS International Initiatives	30 000
PFIZER	EURORDIS International Initiatives	42 000
	EURORDIS International Initiatives	72 000
INTERCEPT	Miscellaneous	2 000
	Miscellaneous Total	2 000
	Grand Total	1 443 631

Company	Purpose	Amount
CYDAN	Round Table of Companies	5 000
IDIS-CLINIGEN	Round Table of Companies	5 000
MAPI	Round Table of Companies	10 000
OpenApp	Round Table of Companies	5 000
QuintilesIMS	Round Table of Companies	25 000
		50 000