

2018 FINANCIAL REPORT



PRESIDENT'S STATEMENT

2018 was a good year for OIFE and important goals were reached.

A long term strategy was developed and we got a new Medical Advisory Board. We developed a new webpage, a magazine and improved our external communication in general. We became more visible as the international umbrella for OI and we got three new member organizations.

The AGM and anniversary celebrations left people inspired and during the AGM we welcomed two new EC-members - Dace Liepina from Latvia and Ida Männistö from Finland.

We also thanked our vice presidents Taco van Welzenis and Eero Nevalainen for their long lasting contributions to the OIFE.

The EC developed new ways of working together through monthly meetings, Google for Non Profits, and tools like Wunderlist and WhatsApp. But even if we work more efficiently, lack of time is the big critical factor. Much of the follow-up between the monthly videocalls falls on the OIFE's president, and the situation is vulnerable.

Considering that we don't have paid staff, our activity level was high in 2018. Perhaps too high? We managed to keep track with the increasing amount of e-mails and requests from individuals and stakeholders who want to work with us.

But it's getting increasingly harder to keep up and one can raise the question if this level of activity is sustainable over time. To keep up with the current activity level and reach goals in our long term strategy, we need more volunteers, more experienced patient representatives and preferably some kind of paid staff.



INGUNN WESTHERHEIM

President

FINANCIAL OVERVIEW

OIFE's financial situation had a slightly positive development in 2018, but we still need more substantial and predictable funding to reach our goal of becoming a professional and efficient umbrella organization.

OIFE does not have many different sources of income besides membership fees, smaller donations and industry support. We're therefore getting closer and closer to a situation where more than 50% of our income comes from industry support. The only company we received support from in 2018 was MereoBiopharma (8000 euros for Flying OI Experts Project).

We received a testamentary gift from Rob van Welzenis in 2018, which have been placed in a separate savings account. The gift was intended as a financial buffer for OIFE, but the OIFE Board can decide to use the gift for a project deemed suitable.

We applied for funding for rare disease federations from EURORDIS and received 2000€ in round two after first being rejected. Other sources of income were membership fees and gifts/donations from individuals/member organizations (mainly NFOI). We made several attempts at being approved for Facebook Donations in 2018, but because we are spread in several countries (registration, bank accounts, board) this turned out to be difficult. We have started a process to develop a financial policy for OIFE, but there is still substantial work that needs to be done.

INCOME AND EXPENDITURE

from 1.1.2018 to 31.12.2018

OIFE accounts	Nr.	c. b. 1.1.2018	c. b. 31.12.2018	difference
Business account	612309	34 093,77 €	28 817,79 €	-5 275,98 €
Daily allowance account	625202	8 770,52 €	8 770,52 €	0,00 €
Savings account	1 709 294	17 920,63 €	17 922,42 €	1,79 €
Rob&Lidy's Fund	8 9350 33	0,00 €	10 001,00 €	10 001,00 €
PayPal Account		280,61 €	516,99 €	236,38 €
Cash		104,06 €	1,03 €	-103,03 €
Total		61 169,59 €	66 029,75 €	4 860,16 €

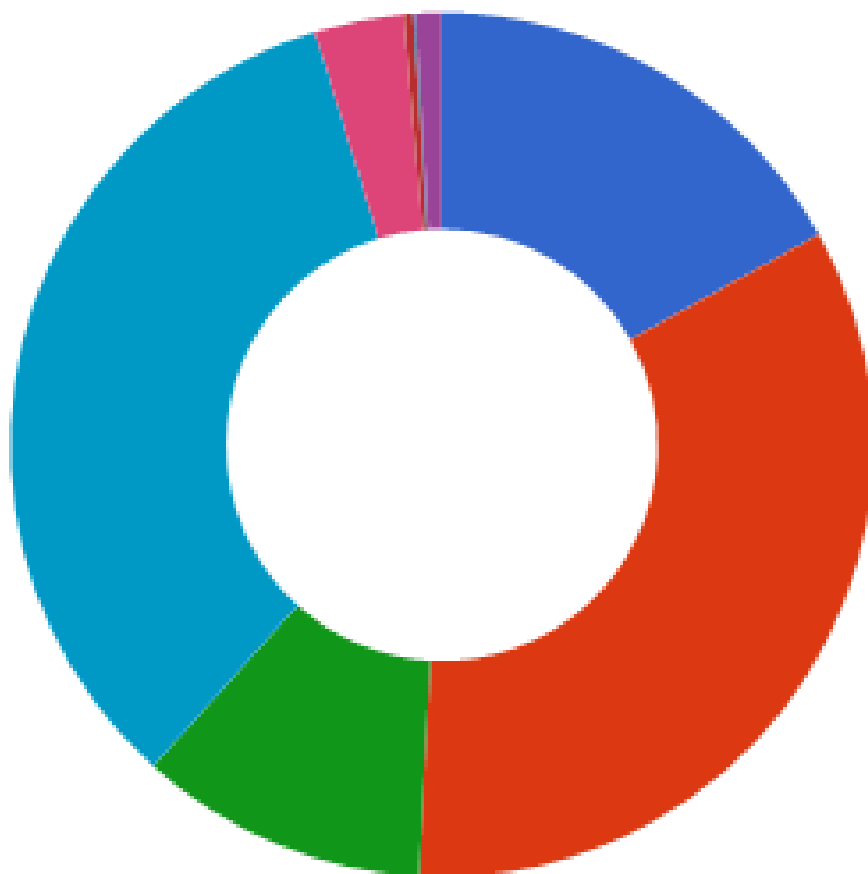


INCOME 2018

by type

		Income
	Membership fees	5 030,00 €
	Non-purpose-related donations	10 102,50 €
	Purpose-related donations and subsidies: (from Pharma 8000€; other 6205,05€)	
by Projects	Flying OI experts	3 215,60 €
	Youth Meeting*	0,00 €
	OIFE´s Communication	10 000,00 €
	OIFE-Pass	989,45 €
	Bank interests	1,79 €
	Amounts brought forward	103,03 €
	Other income	25,00 €
	Miscellaneous	292,32 €
		29 759,69 €

Income



- 17% ■ Membership fees
- 34% ■ Non-purpose-related donations
- 11% ■ Flying OI experts
- 0% ■ Youth Meeting
- 34% ■ OIFE's Communication
- 3% ■ OIFE-Pass
- 0% ■ Bank interests
- 0% ■ Amounts brought forward
- 0% ■ Other income
- 1% ■ Miscellaneous

EXPENDITURE 2018

by type

		Expenditure
Office	Office Supplies	75,00 €
	Postage	342,12 €
	Telephone- and Internetcosts	0,00 €
	Hardware/software costs	650,00 €
Representation	Travel Expenses	
	- EC meetings travel expenses	2 046,85 €
	- AGM travel expenses	6 266,60 €
	- Other travel expenses	2 646,69 €
	Registration fees	199,24 €
	Membership fees	75,00 €
Board	AGM	3 521,34 €
	EC Meetings	2 827,12 €
	Events	0,00 €
Projects	Flying OI experts	494,50 €
	Youth Meeting*	1 200,00 €
	OIFE's Communication (includes Secretary)	4 286,47 €
	OIFE-Pass	0,00 €
Awareness	Marketing costs	52,57 €
	Information costs	0,00 €
	Presents	22,50 €
Other	Amounts brought forward	103,03 €
	Other expenditure	0,00 €
	Bank charges	90,50 €
		24 899,53 €

EXPENDITURE

