

# Fund Rare Diseases and Orphan Drugs

managed by the King Baudouin Foundation

## REPORT OF THE AUGURAL MEETING OF THE MANAGEMENT COMMITTEE 14 DECEMBER 2007

		Present	Excused
Chairman	Jean-Jacques Cassiman	X	
Members	Marc Abramovicz	X	
	Yolande Avontroodt		X
	Marc Bogaert	X	
	Vincent Bours		X
	Lut De Baere	X	
	Vera De Groof	X	
	Marc Doods	X	
	François Eyskens		X
	André Lhoir	X	
	Leo Neels	X	
	Mattias Neyt		
	Claude Sterckx	X	
	François Sumkay	X	
	Erik Tambuyzer		X
	Thierry Vélú		X
Klaartje Bruyninckx (replacing Ilse Weeghmans)	X		
Gerrit Rauws	X		
Secretary	Tinne Vandensande	X	

Start of the meeting: 10.30 am

Next meeting: Friday **22 February 2008** in the offices of the King Baudouin Foundation, from 10:30 to 1:00 pm. Besides all members of the steering group/management committee, the representatives of the (informal) working groups on rare diseases of the university medical centres are invited to attend this meeting.



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## 1. Inauguration of the Management Committee (MC)

<b>Issue</b>	Inaugural meeting 14 December 2007 Mission of the Fund
<b>Comments</b>	Documents: - Composition MC - General guidelines – Funds managed by the KBF
<b>Decisions</b>	<p>Gerrit Rauws, the representative of the King Baudouin Foundation, welcomes the members of the MC; he installs the MC under the chairmanship of prof. Jean-Jacques Cassiman. The set up of the Fund Rare Diseases and Orphan Drugs guarantees a long-term engagement of the KBF. The duration of the Fund is not limited in time. The Fund is endowed with an initial capital of €75.000.</p> <p>The chairman thanks the KBF for showing its trust in the activities of the steering group; he hopes that the Fund will increase the recognition and visibility of the Steering Group. The mission and objectives of the Fund fully correspond with these of the informal Steering Group: ‘to improve the quality of life of rare disease patients and their entourage. The Management Committee/Steering Group aims to initiate and coordinate all actions re rare diseases and orphan drugs in a structural and integrated way’.</p>

## 2. Budget 2008

<b>Issue</b>	The annual budget constitutes 5% of the fund’s capital. For 2008 there is an amount of € 3750 available.
<b>Comments</b>	<p>The Management Committee decides on the use of the annual budget. The Fund’s capital can grow further: via donations or legacies transferred to the KBF.</p> <p>Could the budget also be used to support the national patient association that is under construction, Eurordis Belgium? Eurordis Belgium will unite the rare diseases patient organisations in Belgium. VPP and LUSS are both involved in another project of the KBF on patient involvement in health policy, where the recognition and financing of patient organisations is also put on the agenda.</p>
<b>Decisions</b>	<p>The MC decides to organize an additional fundraising to complement the current budget. The fundraising will be launched via the website of the Steering Group at a later stage when the actions are better defined and project planning has been developed further. Donations of € 30 or more are tax deductible in Belgium.</p> <p>KBF doesn’t exclude the financing of patient organisations via other activities and instruments of the Foundation.</p>

### 3. Approval of the action points of the previous meeting

<b>Issue</b>	Action points – meeting Steering Group, 8 October 2007
<b>Comments</b>	<ul style="list-style-type: none"><li>- Yellow Window, a management consultancy firm, based in Antwerp, has requested the collaboration of the Steering group as an expert advisory group for the submission of a proposal to the KCE-call re the orphan drugs (closing date 19 December 07).</li><li>- Two working groups are preparing the establishment of Eurordis Belgium: WG1 draws the articles of the association; WG2 prepares the Rare Diseases Day on the 29<sup>th</sup> of February 08.</li><li>- The proposal of Yolande Avontroodt drafted for the Federal Parliament has been submitted again on the 5<sup>th</sup> of December 07.</li></ul>
<b>Decisions</b>	<ol style="list-style-type: none"><li>(1) The members agree to work together with Yellow Window. The Steering group will be represented in the application by a series of medical experts.</li><li>(2) Mark Bogaert makes the list of orphan drugs available, reimbursed in Belgium – status December 2007 (<i>see appendix</i>).</li><li>(3) Regarding the Orphanet Belgium website, a network of experts is needed for answering the questions raised by the visitors of the site.</li></ol>

### 4. Consultation regarding Community action on rare diseases

<b>Issue</b>	Public Consultation regarding European action in the field of Rare Diseases.
<b>Comments</b>	English document made available; other languages can be consulted on the EC website: <a href="http://ec.europa.eu/health/ph_threats/non_com/cons_rare_dis_en.htm">http://ec.europa.eu/health/ph_threats/non_com/cons_rare_dis_en.htm</a> Responses to this consultation, focused around the specific questions identified in the text, should be sent to the European Commission by <u>14 February 2008</u> .
<b>Decisions</b>	All members are invited to send their comments and suggestions to Jean-Jacques Cassiman before the 10 <sup>th</sup> of January 2008.

### 5. Planning of activities

<b>Issue</b>	Activities 2008
<b>Comments</b>	<ul style="list-style-type: none"><li>- The proposal made by the Steering group for the research programme of the KCE 2008 has been taken up partly (see the call definition). How will the Steering Group proceed on issues of prevalence, diagnosis and treatment? It seems that there are initiatives at the UA and VUB to map the Belgian situation. Can we confine a mission to a research institution to provide a good status of the rare diseases in Belgium, listing the problems experienced by health care providers?</li><li>- The idea of ‘discussion-café’s for patients and public has been suggested. Other formats like ‘dementia-café’s or ‘science-café’s could be used as inspiration.</li><li>- Progress needs to be made on the translation/rethinking of the French ‘Plan National Maladies Rares’ towards the Belgian situation.</li></ul>

**Decision**

The members decide to start with an informal, intermediary stage during which the 7 university medical centres are invited to reflect and discuss on how the management of rare diseases is organized currently and how it could be improved. The first casus on the agenda will be the multidisciplinary group of the University Hospital Leuven (contact person: Marc Doods). The contact persons of the other medical centres will be invited to participate to these casus-meetings. All members prefer to organize these meetings in situ. For practical reasons the next meeting will be held in offices of the KBF.

The contact persons below are requested to send a list of invitees for the next meeting:

Marc Abramovicz: ULB

François Eyskens: UA

Marc Bogaert: Ugent (done)

Marc Doods: UZ Leuven

Vincent Bours : Ulg

For VUB it was suggested to invite Linda de Meirleir

For UCL: Mikka Vikkula

**6. Others**

The next meeting will be held on Friday 22 February in the 'Raadzaal/ Salle du Conseil' of the KBF. Starting hour: 10.30 am.