

ADDENDUM 2 : Template of Committee annual report

(all cells can be expanded as needed)

Committee chair

Name of committee : Patient committee		
Chair : Elke Stienissen	Since : November 2020	Date of last election : November 2022

Committee members : name (E-mail)

Mariangela Fiorente (ALWB asbl : lymphoma)	mariangela.fiorente@alwb.be
Delphine Margerin (ALWB asbl : lymphoma)	dmj.margerin@gmail.com
Jeannot Poelman (secretary – CMP Vlaanderen vzw : multiple myeloma and waldenström's disease)	jeannot@cmpvlaanderen.be
Wim Koolen (CMP Vlaanderen vzw : multiple myeloma and waldenström's disease)	wim@cmpvlaanderen.be
Mimi M. Maboloko (collectif drépanocytose asbl : sickle cell disease)	collectif.drepanocytose@gmail.com
Jean Pierre Blondeel (Hodgkin en non-Hodgkin vzw : lymphoma)	ipblondeel.hodgkin@gmail.be
Sandra Van Grimberge (Lotuz vzw : allogeneic stem cell transplant)	sandra@lotuz.be
Elke Stienissen (chair – Lymfklierkanker Vereniging Vlaanderen vzw : lymphoma and CLL)	elkestienissen.lvv@gmail.com
Rob Van Hees (MPN Facebookgroep België : polycythemia vera, essential thrombocythemia and myelofibrosis)	rob.mpnbelgie@gmail.com
Gay Charles (Mymu Wallonie-Bruxelles asbl : multiple myeloma)	gaycorinne.charles@gmail.com
Claudine Kalubi (Sang pour sang asbl : sickle cell disease)	Masens_k@msn.com
Philippe Vindevogel (Stichting ME TO YOU : blood related diseases)	info@stichtingmetoyou.be
Robert Scheltjens (SuperNils vzw : hematology in general)	Robert.scheltjens@supernils.be
Kevin Claes (TTP community: Thrombotic thrombocytopenic purpura)	claes799@hotmail.com
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Marijke Quaghebeur (Cristina Baiana)	marijke.quaghebeur@uzgent.be (cristina.baiana@uclouvain.be)
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Prof. Timothy Devos Dr. Ann Van de Velde Prof. Chantal Doyen Dr. Bailly	timothy.devos@uzleuven.be ann.van.de.velde@uza.be chantal.doyen@uclouvain.be Benjamin.BAILLY@jolimont.be
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Activities in year 2022

Date	Activity
January 10 th	Committee meeting
February 22 nd	Presentation patient committee at the lymphoma committee
February-April	Review CML videos (Pfizer) Global patient survey for patients with lymphoma, CLL and WM (Lymphoma Coalition)
March	Review ITP patient brochure (Novartis)
March 24 th	Committee meeting
April 23 rd	ITP Patient day: introduction and presentation BHS patient committee
May 18 th	Committee meeting
September 20 th	Committee meeting
November 14 th	Committee meeting
February	Recent advances in the treatment of CLL : bringing the patient into the equation (BHS GAM) Presentation patient committee (BHS Nurse symposium)
During the whole year	Review clinical trial brochure (dr. Heyrman)
During the whole year	Review immunotherapy brochure (Gilead)
During the whole year	Project art work (Pfizer)
During the whole year	Review website AstraZeneca
During the whole year	Review brochures vivre avec un lymphoma, Waldenström and 'multiple myeloma (Janssen oncology) + review brochure multiple myeloma (BMS)
During the whole year	Presentation of the flyer and website for patients with blood diseases
! Please provide minutes of all this year's committee meetings !	

Publications in year **2022**

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Plan (policy, activities with approximate dates...) for next year

Committee meetings:

- January 16th
- March 13th
- May 15th
- September: to be determined
- November: to be determined

Policy:

SOP for the co creation of patient materials

Activities

Website and flyer for patients with information about hematological diseases and all hematological patient organizations.

Our goal is to make **1 flyer** that contains all patient organizations. This has the advantage that every hospital in Belgium can give this flyer to patients when they get their diagnosis. Up till now all (patient) organizations have their own flyer.

Besides the flyer we also want to help with creating a **patient corner** on the BHS website with information for patients and caregivers.

Comments / requests for the BHS board

1. Flyer and mini website – awareness

We want to make **1 flyer** with basic information about the disease and (patient) organizations which we will link to the patient corner on the BHS website.

The flyer will contain all hematological patient organizations that are a member of our committee and it will replace all the separate flyers from the individual (patient) organizations. This means that 1 flyer can be given to every patient with a hematological disease.

For this project we would like to have :

- Some financial support from the BHS
- Input from the health care professionals (explanation on the disease and treatments)
- Communication from the BHS to notify the hematology hospitals about the flyer and to advise them to hand out the flyer to patients with a hematological disorder

2. Patient information

We want to provide the patient's perspective on patient information, care improvement and scientific projects. Therefore we would like to **work together with the BHS board and other committees**: a lot of pharmaceutical companies ask us to review their patient materials from a patient view. Is the text understandable, what is missing, Some of those brochures are reviewed by haematologists as well from a medical view. But it is not because something is medically or scientifically correct that it is also patient friendly and understandable for patients and caregivers. We want to work closely together so new patient materials can be created and we want to avoid creating patient materials that already exist. We would like to collaborate further with the board and other committees to make guidelines that address all the concerns that we have, f.e. workload.

3. BHS Gam

We would like to have 1 topic at the scientific meeting that is a collaboration between the BHS board, BHS nurse committee and BHS patient committee

4. emailaddress

We would like to have a BHS patient committee **email address** so patients can reach out to our committee for support. We will also need this as soon as the patient corner is available.

5. Social media channels

Besides a professional LinkedIn-page we would like that BHS has a

- Facebookpage
- Instagrampage
- Twitter page
- YouTube-channel

It would be nice if BHS could download webinars, pictures of the award winners and the BHS Gam etc. on those channels. These platforms are the ideal channels to reach out to patients and to inform patients about BHS and the BHS patient corner.